'No one bothers about the confused people': Care for people with psychosocial disabilities in rural South Africa

by

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Dissertation presented for the degree of Doctor of Philosophy in the Faculty of Arts and Social Sciences at Stellenbosch University

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December 2016

Declaration

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

December 2016

Abstract

This dissertation explores care for people with psychosocial disabilities in a rural area in the Eastern Cape province of South Africa.

In Low and middle-income countries, including South Africa, the gap between the need for mental health services and available services is critical. Reasons for this have been said to be lack of priority at policy level, lack of equipment, personnel, and medication, and low mental health literacy. As a result, the majority of people with psychosocial disabilities are not diagnosed or treated. In order to close the gap between need and provision, there is a call for more community based mental health services, for task-shifting and a move towards recognising medical pluralism. There is lack of evidence on family and community care, traditional systems of healing and medical pluralism. Care is often reduced to health care, but arguably also includes assistance with daily tasks, companionship, conversation and intimacy. Explanatory models for psychosocial disability are crucial in care seeking, diagnosis, treatment and cure. As such, the theoretical points of departure for this dissertation are the concepts of psychosocial disability and care.

The aim of this study was to explore practices, views, knowledge and experiences related to care for people with psychosocial disabilities living in a rural, South African context. To do this, a qualitative methodology was deemed suitable. The study is divided into two linked, but methodologically different parts, namely a contextual part and a case study part. The overarching methodological principles are the same; they are both anchored within a qualitative, explorative research design.

The dissertation has found that in the context of psychosocial disability in Madwaleni, care is much broader than health care, and about much more than curing illness or looking after someone who is ill or dependent. In an attempt to improve mental health, and prevent, treat and cure mental disorder, it is essential to apply a broad definition of care. We need to rethink how we deliver mental health services, moving away from care as pacifying, to care as activating. Care must be integrated into real-world settings. The global mental health literature emphasises shifting the focus of mental health care from cure to promotion and prevention. It also stresses the value of using an interdisciplinary team of lay and trained health workers from the professional, folk and popular sectors. This strategy needs to be complemented by other strategies, for example, integrating mental health into other projects focussing on sustainable livelihoods and development of infrastructure. The challenges are complex, as this small study shows, but it is only by looking closely at local conditions that it is possible to develop culturally and contextually appropriate interventions and make optimal use of local resources.

Opsomming

Hierdie verhandeling ondersoek sorgverskaffing aan persone met psigososiale gestremdhede in ’n landelike gebied van die Oos-Kaapprovinsie, Suid-Afrika.

In lae- en middelinkomstelande, waaronder Suid-Afrika, is die gaping tussen die behoefte aan geestesgesondheidsdienste en die diensaanbod kritiek. ’n Gebrek aan beleidsvoorrang, ’n tekort aan toerusting, personeel en medisyne, sowel as lae geestesgesondheidsgeletterdheid word as redes hiervoor aangevoer. Gevolglik word die meeste mense met psigososiale gestremdhede nie gediagnoseer of behandel nie. Om hierdie gaping tussen vraag en aanbod te oorbrug, is daar ’n oproep om meer gemeenskapsgebaseerde geestesgesondheidsdienste, taakoordrag en ’n verskuiwing na die erkenning van mediese pluralisme. Daar bestaan weinig bewyse in verband met familie- en gemeenskapsorg, tradisionele genesingstelsels en mediese pluralisme. Onder ‘sorg’ word dikwels gesondheidsorg verstaan, maar dit sluit stellig ook bystand met daaglikse take, kameraadskap, gesprek en intimiteit in. Verklarende modelle van psigososiale gestremdheid is noodsaaklik in die soeke na sorg, diagnose, behandeling en genesing. Daarom is die teoretiese uitgangspunte vir hierdie verhandeling die konsepte van psigososiale gestremdheid en sorg.

Die doel van hierdie studie is om praktyke, sienings, kennis en ervarings met betrekking tot die versorging van mense met psigososiale gestremdhede in ’n landelike, Suid-Afrikaanse omgewing te ondersoek. Hiervoor word ’n kwalitatiewe metodologie as gepas beskou. Die studie word in twee verbandhoudende dog metodologies verskillende afdelings ingedeel, naamlik ’n kontekstuele afdeling en ’n gevallestudieafdeling. Die oorkoepelende metodologiese beginsels is dieselfde; albei afdelings is in ’n kwalitatiewe, ondersoekende navorsingsontwerp veranker.

Die verhandeling bevind dat sorg, in die konteks van psigososiale gestremdheid in Madwaleni, veel verder as gesondheidsorg strek, en ook oor veel meer handel as die genesing van siekte of die versorging van iemand wat siek of afhanklik is. In ’n poging om geestesgesondheid te verbeter en geestesteuring te voorkom, te behandel en te genees, is dit noodsaaklik om ’n breë omskrywing van sorg toe te pas. Ons moet nuut dink oor hoe ons geestesgesondheidsdienste lewer, en wegbeweeg van die gedagte van sorg wat kalmeer tot sorg wat aktiveer. Sorg moet by die omstandighede van die werklike wêreld geïntegreer word. Wêreldliteratuur oor geestesgesondheid onderstreep die belang van ’n klemverskuiwing in geestesgesondheidsorg van genesing tot bevordering en voorkoming. Dit beklemtoon ook die waarde van ’n interdissiplinêre span leke- en opgeleide gesondheidswerkers uit die professionele, volks- en populêre sektore. Hierdie strategie moet aangevul word met ander

strategieë, soos die integrasie van geestesgesondheid by ander projekte met die oog op ’n volhoubare bestaan en die ontwikkeling van infrastruktuur. Die uitdagings is kompleks, soos hierdie beperkte studie toon, maar slegs deur plaaslike omstandighede indringend te bestudeer, kan ons kultureel en kontekstueel gepaste intervensies ontwikkel en plaaslike hulpbronne optimaal benut.

Acknowledgements

First, and foremost, I would like to extend my sincere gratitude to my supervisor, friend and colleague, Professor Leslie Swartz. Without him I would not have had the opportunity to do this PhD, and without his guidance and support I would not have been able to complete this dissertation. Leslie is an inspiration to me both as an academic and as a human being. I feel privileged to have been his colleague and student for more than a decade.

I would also like to thank my employer and my colleagues for the past 11 years, SINTEF Technology and Society, Department of Health. I would particularly like to thank Professor Arne Eide for reading and commenting on this dissertation, and providing me with professional support throughout my research career and my PhD.

I would like to thank the entire EquitAble team from Ireland, Sudan, Malawi, Namibia, Norway and South Africa. A special thank you to the South African team members, Professor Leslie Swartz, Dr. Gubela Mji, Dr. Margie Schneider, Janis Kritzinger, Dr. Richard Vergunst and Dr. Surona Visagie.

This research was made possible due to funding received from the European Commission FP7 (Grant Agreement No. 223501) and from Department of Science and Technology, South Africa.

Thank you to the people who assisted me during my fieldwork; my interpreters, health workers and members of the local community who helped me find informants and who participated as informants. A very special thank you to Vasco Ju Ju.

For their assistance with language translations, I would like to thank Dr. Gubela Mji and Professor Mawande Dlali at Stellenbosch University. I would also like to thank Dr. Bonginkosi Chiliza and Dr. Laila Asmal for reading and commenting on the six case studies. Thank you also to Jacqueline Gamble for an excellent job editing this dissertation.

A big thank you to the three examiners of this dissertation for their valuable input and comments towards the final version; Professor Edvard Hauff, Professor Inge Petersen and Professor Lana van Niekerk.

Last, but certainly not least, I am incredibly grateful for and thankful to the wonderful web of people I surround myself with in my everyday life in my home country, Norway. People with whom I am highly interconnected. Thank you for listening to my frustrations, for supporting me and believing in me. I am who I am because we are.

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List of Abbreviations

CBMHS	Community based mental health services
CHW	Community health workers
GMH	Global mental health
LMICs	Low and middle-income countries
OPD	Outpatient department
OT	Occupational therapist
PT	Physiotherapist
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Outputs from PhD

Some aspects of this dissertation have been published in an article in *International Health*:

Braathen, S. H., Vergunst, R., Mji, G., Mannan, H., & Swartz, L. (2013). Understanding the local context for the application of global mental health: a rural South African experience. *International Health 5*(1), 38-42.

Outputs from the dissertation have also been presented at several conferences and meetings, including:

- Disability and Global Health (Bergen, Norway, June 2016).
- International Congress of Psychology (ICP) (Cape Town, South Africa, July 2012).
- 2nd Annual Malawi Mental Health Research and Practice Development Conference (Blantyre, Malawi, March 2012).
- AfriNEAD (The African Network for Evidence to Action in Disability) symposium (Victoria Falls, Zimbabwe, November 2011).

Chapter One: Introduction

1.1 Problem statement

This dissertation will explore care for people with psychosocial disabilities in a rural area of the Eastern Cape province of South Africa.

Psychosocial disability is commonly referred to as mental disorder or mental illness in the literature. I have chosen to primarily use the term psychosocial disability because of the disabling nature of mental disorders. I will, however, also use other terminologies as they are used in the literature and by informants in this study. Issues of terminology will be discussed below.

People with disabilities, including people with psychosocial disabilities, are among the most vulnerable and marginalised groups of any population. They are often excluded from mainstream social, economic and health services, lacking educational and occupational opportunities to meet their full potential (Eide & Loeb, 2006; Eide, Nhiwatiwa, Muderedzi, & Loeb, 2003; Eide, van Rooy, & Loeb, 2003; Groce, 2004; Lancet, 2009; Loeb & Eide, 2004; Loeb, Eide, Jelsma, Ka'Toni, & Maart, 2008; WHO, 2010a). People with psychosocial disabilities commonly experience reduced access to medical, psychological and social services for a number of reasons, ranging from personality traits and individual characteristics relating to the psychosocial disability, to attitudes and beliefs about psychosocial disability from the health service providers (Horton, 2007; Leucht, Burkard, Henderson, Maj, & Sartorius, 2007; Prince et al., 2007; WHO, 2001a, 2010a). Issues of access to services are even more pronounced for people living in poor, rural areas (Iezzoni, Killeen, & O'Day, 2006; Lishner, Richardson, Levine, & Patrick, 1996).

Psychosocial disabilities affect people's quality of life and social participation (Andrews & Titov, 2007; Bobes, Caballero, Vilardaga, & Rejas, 2011). Mental disorders are leading causes for disability and major causes for mortality worldwide (Patel & Stein, 2015), and as such, psychosocial disabilities make up a large proportion of the overall burden of disease. On the one hand, they are risk factors for communicable and non-communicable diseases, as well as accidental and non-accidental injuries. One the other hand, many physical health conditions are risk factors for mental disorders. This co-morbidity complicates diagnosis, help-seeking and treatment. Thus, there can be "no health without mental health", as the well-known slogan goes (Hanlon, Fekadu, & Patel, 2014; Horton, 2007; Leucht et al., 2007; Lund, Petersen, Kleintjes, & Bhana, 2012; Patel, 2014; Prince et al., 2007; Prince, Rahman, Mayston, & Weobong, 2014; Stein, Williams, & Kessler, 2009; WHO, 2001a). Hence, mental disorders are of major importance for public health, but they are usually not part of mainstream efforts to

improve health and reduce poverty (Prince et al., 2007; Raviola, Becker, & Farmer, 2011). It is estimated that almost a third of the South African population will experience episodes of psychosocial disability in their lifetime (Herman et al., 2009).

Many people with psychosocial disabilities living in low and middle-income countries (LMICs) face violations of their human rights, such as inability to access appropriate health services, stigma, discrimination, and inability to exercise legal, civil, social and political rights (Dhanda & Narayan, 2007; Drew et al., 2011). Within a United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) framework, these individuals are entitled to appropriate support and accommodation to exercise their human rights (Dhanda & Narayan, 2007; Drew et al., 2011; United Nations, 2006). It is well established that investing in mental health is essential to enhance individual and population health and well-being, protect human rights, improve economic efficiency and achieve universal health coverage. Despite this, across the world, people with psychosocial disabilities are stigmatised, discriminated against and denied their basic rights, including access to appropriate care (WHO, 2013a). In LMICs in general, and in South Africa specifically, mental health issues have low priority, and people with psychosocial disabilities face multiple stigmatisations and discriminations which undermine their participation in society and in mental health policy and programme development (Kleintjes, Lund, & Swartz, 2013a).

WHO calls for stakeholders and governments to increase priority for mental health and address identified barriers and shortcomings, including better information, awareness and education about mental health and mental disorder; improved health and social services for people with mental disorders; and better legal, social and financial protection for individuals, families and communities affected by mental disorders (WHO, 2013a).

There is a scarcity of empirical evidence about actual experiences at the interface between psychosocial disability, culture, context and care, which is the area of research for this dissertation.

1.2 Objectives and research questions

The objective and research questions for this project were informed by existing literature, theoretical concepts and contextual factors (Crowe et al., 2011). ***The overall objective of this dissertation is to explore structures of care for people with psychosocial disabilities in Madwaleni, emphasising on the following broad research questions:***

- How are people with psychosocial disabilities cared for at various levels/by various people and institutions? For instance:
    - Individual (self-care/help-seeking)

  - Family
  - Community/neighbours/friends
  - Health services; professional and folk sectors
  - Religious societies/institutions
  - NGOs
  - Other
- What is the rationale for choosing and applying the different care strategies for and by the various people?
- How are these care strategies implemented and with what reported outcomes?

1.3 Origin and placement of dissertation

This PhD dissertation is part of a large, multidisciplinary and international research project studying the relationship between vulnerability and access to health care in resource poor settings in Namibia, Malawi, Sudan and South Africa (EquitAble)[1]. The project was funded by the European Commission's Framework Programme 7; Project title: Enabling Universal and Equitable Access to Healthcare for Vulnerable People in Resource Poor Settings in Africa (Grant Agreement No. 223501). The overall project consisted of five work packages (WP), and four or five sites in each country. This PhD is linked to WP3 in EquitAble (Intensive qualitative studies), and one of the four South African sites (Madwaleni). The timeframe for the overall EquitAble project was 2010-2013, and the data collected for this dissertation as part of that project were collected during that time.

The PhD also uses contextual and background data from another project studying access to health services for people with disabilities in South Africa and Malawi. The project was funded by the Norwegian Research Council, under the GLOBVAC programme (Project number 183650/S50). This dissertation will draw upon data from the qualitative component in the South African site (Madwaleni) collected in 2008.

While the two projects described above have emphasised broadly on vulnerability and disability, this PhD has narrowed the scope to people with psychosocial disabilities, a group that is commonly described as vulnerable, but perhaps less commonly included in the field of disability research. In addition to the data collections connected to the two projects described above, I also carried out two data collections in 2011 and 2012 solely for the purpose of this PhD.

This dissertation is at the intersection of a number of overlapping fields including public health, medical anthropology, public mental health, cultural psychology, occupational science and

[1] EquitAble project: www.equitableproject.org

disability studies. I will thus draw upon methodological principles and theoretical points of departure from all of these disciplines. Given the interdisciplinary positioning of the study, however, I will not be able to do justice to all these fields of enquiry, and I shall draw on primary approaches which are most appropriate to my research questions.

1.4 Study context

Figure 1. Eastern Cape Province, Amathole District Municipality and Mbashe Local Municipality[2]

1.4.1 South Africa

South Africa is a diverse and multicultural country, with a population of almost 54 million people, comprising 80,2% Black African, 8,8% Coloured, 8,4% White and 2,5% Asian. The country has 11 official languages and nine geographical provinces. Almost 40% of the population live in rural areas (CIA, 2016; Statistics South Africa, 2016). It is considered an upper middle-income country (The World Bank, 2016), but with high levels of inequality, attributed largely to the legacy of apartheid (Mooney & McIntyre, 2008).

[2] Map from: http://www.nwga.co.za/images/gallery/Map.jpg

Apartheid is an Afrikaans (one of the official languages of South Africa) word meaning "separateness" or "setting apart", which in apartheid South Africa translated to separating each race into assigned geographical zones. South African racial politics led to major inequalities in the population, with those fitting in to the racial category Black African being the most disadvantaged group (WHO, 1983). During the Apartheid era in South Africa, grave human rights abuses were committed in the name of psychiatry and mental health. Indeed, the man credited as the father of Apartheid in South Africa, Hendrik French Verwoerd, was a lecturer in psychology at Stellenbosch University. Apartheid stems from a pseudoscientific discipline called eugenics, focusing on racial differences and racial superiority, with the main argument being that controlled selective breeding would improve the human race. Psychiatric genetics was studied as part of this field, with the argument that certain races were psychologically superior. The scientific discipline later formed the basis for various discriminatory laws and acts under the Apartheid government of South Africa, such as policies of separate development, separate freedoms and segregation, which were thought to protect and care for all segments of the population, especially the "natives" (Black Africans). However, history has shown that the laws did not protect and care for most of the South African population, but rather hindered development and forced generations of Black South Africans into unemployment, poverty, poor education and poor health (Burke, 2006). During the apartheid era in South Africa racial and cultural differences were used to justify discriminatory treatment, also in the field of mental health, arguing that the different races with different cultures have different needs, and thus need different treatment. The result was what are today considered highly unequal and discriminatory practices (Swartz, 1996). South Africa is a young democracy of just over 20 years. The country is commonly referred to as a "postconflict society" (O'Mahony, Doak, & Clamp, 2012), where one would expect levels of violence and trauma to decrease, population health to improve, and the gap between rich and poor to narrow. This is highly disputed, however, as the continued high levels of crime, violence and brutality, combined with increased inequality in the country does not justify such a claim (Swartz, 2014a).

The World Health Report, "Working Together for Health" (WHO, 2006) noted that Africa has the greatest disease burden of any continent but has the poorest health services. Despite the relative wealth of South Africa compared to other countries in the region, universal and equitable access to health care is far from achieved (Barron & Roma-Readon, 2008; WHO, 2006), and the country is still grossly under served in terms of mental health services compared to wealthier countries (Swartz, 2007). When the ANC-led democratic government came to power in 1994, health policies were among the first policies to be given attention (Gray & Clarke, 2000). In 1995, the government ordered a review of human rights abuses committed in psychiatry throughout the country, as well as a revision of the Mental Health Act (Burke,

2006). The new government emphasised on fundamental improvements in basic infrastructure, as well as poverty alleviation strategies. Funding was moved away from large sophisticated hospitals towards primary health care facilities. Despite these reforms, equitable access to health is still out of reach in South Africa (Barron & Roma-Readon, 2008; WHO, 2006). Poverty is still rampant for a large majority of the South African population. Poverty is linked to past history where apartheid played a major role, but also to the uneven distribution of wealth and welfare goods in today's society (Crais, 2002).

A large proportion of the South African population are dependent on social grants, such as child support grants, care dependency grants or disability grants, for survival. More than 1.3 million South Africans receive disability grants (Statistics South Africa, 2014). In the context of widespread poverty, social grants have become the main means of existence for many families. While this money may prevent complete destitution for individuals and families, it is not enough to escape poverty completely (Surender, Ntshongwana, Noble, & Wright, 2007). It appears, however, that if disability grants are combined with other grants such as old age pensions and child support grants, these grants may provide rural households with sufficient amounts of money to prevent dire poverty (Hansen & Sait, 2011).

1.4.2 Eastern Cape

The study area for this dissertation is located in the Eastern Cape Province of South Africa, one of the poorest provinces in the country. The province covers an area of 168 966km² and has a population of 6 562 053. The majority of the population are Black African, primarily isiXhosa speaking. This makes it the second largest province in the country, with the third largest population (The Local Government Handbook, 2016a). Social grants are an important source of income for individuals and households in this part of South Africa. Forty percent of the population receive some form of social grant, and at household level, almost 60% of all households receive at least one social grant. This is the highest in the country. Only 10,7% of the population in Eastern Cape has private medical aid. This is among the lowest in the country, and it is even lower in rural areas and among the Black population (Statistics South Africa, 2016).

Eastern Cape is one of the provinces with the lowest access to piped water and sanitation services in the country (Barron & Roma-Readon, 2008; Statistics South Africa, 2016). The distribution of health workers in South Africa is unequal, and the patient-provider ratio is disproportionately low in the Eastern Cape Province, with 13,5 doctors to a population of 100 000, compared to Western Cape which has 25,2 doctors per 100 000 (Barron & Roma-Readon, 2008).

Amathole District Municipality is located in the central part of Eastern Cape Province. It covers an area of 21 595km², with a population of 892 637 (The Local Government Handbook, 2016b). Mbhashe Local Municipality is part of Amathole District Municipality. It is located in the south-eastern parts of the Eastern Cape Province. It covers an area of 3 169km², with a population of 254 909 (The Local Government Handbook, 2016c).

As one of the poorest, most highly populated and neglected rural areas in South Africa, Eastern Cape was one of the areas targeted for the new South African Government's health care reforms. Poor infrastructure exposes people residing in areas like Amathole district to a variety of health hazards. Lack of clean water and good sanitation combined with poor hygiene creates a number of health threats, including epilepsy, caused by the tapeworm Taenia solium usually found in fecally contaminated water and undercooked pork (Veary & Manoto, 2008). Other major health threats in the Amathole district are Tuberculosis and HIV/AIDS, diseases that go hand in hand with high morbidity. There are indications that people with disabilities living in rural settlements such as the study area report lower health related quality of life than people in urban living (Jelsma, Maart, Eide, Ka'Toni, & Loeb, 2007).

1.4.3 Madwaleni

Madwaleni community, the study area for this dissertation, is part of Mbhashe Local Municipality in Amathole District Municipality in the Eastern Cape Province of South Africa. Madwaleni is deeply rural, and one of the poorest, most under-served and historically neglected areas in South Africa (Barron & Roma-Readon, 2008). Madwaleni Secondary Hospital was built by the Dutch Reformed Missionaries in 1960, and taken over by the Eastern Cape Department of Health in the 1990s. The 180-bed hospital serves a population of more than 250 000 from communities Elliotdale, Mqanduli, Dutywa, Willowvale and parts of Mthatha. Since the advent of democracy in 1994, and as a result of the implementation of primary health care policies, eight local clinics have been built in the hospital's catchment area. The clinics are spread evenly around in the hospital catchment area. The clinics are nurse-driven, staffed primarily by nurses and community health workers (volunteer lay health workers). Madwaleni hospital is 96 km from Mthatha and Nelson Mandela Academic Hospital, which is its referral institution (Madwaleni Hospital, 2016; Province of the Eastern Cape, 2005-2013).

1.4.4 AmaXhosa people

AmaXhosa people comprise the majority of the population of the Eastern Cape in general and Madwaleni specifically. They are a group of clans within the Nguni, Bantu-speaking people in southern Africa, divided into the clans of Mfengu, Thembu, Mpondo, Mpondomise, Bhaca and Bomvana. Most people in Madwaleni belong to the Bomvana clan. The clans are different in

terms of their history, territory, dialect and cultural practices. On a more general basis, all the clans are patrilineal, hierarchical, held together by kin networks and chiefdoms, guided by ancestors in their cultural practices and customs (Duncan, 2009; Duncan, Swartz, & Kathard, 2011a). Xhosa culture has been described as strongly resistant to change, and thus it may be difficult to apply Western oriented procedures in health and medicine to this group of people (Cheetham & Cheetham, 1976). Physical and mental illnesses are bound up in complex belief systems, with culture bound syndromes and culture specific events closely linked to the understanding and treatment of illnesses. There is widespread use of traditional healers in the management of various health conditions among amaXhosa people (Mzimkulu & Simbayi, 2006; Niehaus et al., 2004). Furthermore, they have been said to live closely to nature, and trees and plants, for instance, can have mythical or symbolic influences in addition to their medicinal values. Bührmann (1984) describes the world of the umXhosa healer and his people as primarily intuitive, non-rational and oriented towards the inner world of symbols and images of the collective unconscious. This is in contrast to the Western world, which is primarily scientific, rational and ego-oriented (Bührmann, 1984). Though the neat distinction between “African” and “Western” worldviews has been strongly questioned (Swartz, 1998), it remains important to be open to understanding differing interpretations of the world when working in this context.

An important part of the culture in many parts of Africa, including among amaXhosa people, is the African philosophy of Ubuntu. Ubuntu is described as a philosophy of solidarity, with humanity and compassion as key values. In this philosophy an individual is seen not as isolated, but as part of a group, a family, or a community (Berg, 2003). Ubuntu is a form of social organisation common in many parts of southern Africa, including Madwaleni. It emphasises collectivity rather than individualism, and the core of the philosophy is that humanness is expressed through social interaction. Individuals are often not seen as belonging to themselves or their families, but to society as a whole (Engelbrecht & Kasiram, 2012; Kaseje & Mpenda, 2002; Kirmayer & Swartz, 2014).

This dissertation is not an in-depth exploration of amaXhosa customs and culture, and as such it does not do justice to the extensive literature on these topics.

1.5 Dissertation Outline

In the following sections of this dissertation I will provide an overview and introduction into the concepts of psychosocial disability and care. First, as they are described in the literature and then as they are described, understood and practiced in the context of Madwaleni.

In Chapter Two I describe the conceptual frameworks for the concept of psychosocial disability and the concept of care.

In Chapter Three I provide an overview of the empirical evidence that exists in the field of care for people with psychosocial disabilities, especially in relation to people living in contexts of poverty and resource deprivation in general and in South Africa specifically.

Chapter Four is a description of the qualitative methodology and data collection techniques used to collect data for this dissertation.

In Chapter Five I present results from what I refer to as the contextual study, which gives an introduction to the Madwaleni community and important structures of care available in that context. This chapter gives the contextual background for the next chapter.

Chapter Six is the second results chapter, which presents six qualitative case studies operating within the context that was presented in Chapter Five.

In Chapter Seven, the discussion chapter, I describe and discuss the various care strategies available in the context of Madwaleni, why the various strategies are chosen and with what reported outcome. I discuss how these findings are relevant to, add to or reject what has been found and argued in previous empirical and theoretical literature.

In the final chapter, Chapter Eight, I provide some concluding reflections on how this study has provided new knowledge, what knowledge gaps still exist and recommendations to care for people with psychosocial disabilities in Madwaleni.

Chapter Two: Conceptual framework

2.1 Chapter outline

There are two central concepts to this dissertation, namely psychosocial disability and care. The first section (2.2) will set the stage for the concept of psychosocial disability and its use throughout this dissertation. I will describe major approaches to mental disorder, and how a particular approach places itself within the field of disability. I will also outline different approaches to understanding psychosocial disability. Next (2.3) I will describe and discuss the concept of care, and various approaches to caring for people with psychosocial disabilities.

Cultural and contextual factors are key towards understanding the concepts of psychosocial disability and care.

Culture is described as "a set of rules and guidelines that inform society about ways in which to experience and behave in the world" (Swartz & Rohleder, 2008, p. 541). Culture is not static, but changes over time along with the complex and flexible ways in which human beings live their lives. It has been argued that no individual is fully representative of a culture, and that the most important thing is to attempt to provide a broad and balanced view, aiming to understand different points of view and different forms of internal logic. We must be careful not to assume that everyone within a particular culture, context or society is the same. This assumption risks ignoring individual ways of being and different identities (Kirmayer & Swartz, 2014; Kleinman & Benson, 2006a; Swartz & Rohleder, 2008). Kleinman (1980, 1987, 1988) and others (Helman, 2007; Swartz, 1998) emphasize the pervasive relationship between culture and psychosocial disability.

Contextual factors are also referred to in the literature as social factors, social determinants or social phenomena. The terms are used interchangeably in the literature, but broadly refer to the same phenomena. In this dissertation, contextual factors are taken to include environmental (i.e. social environment, family, community, networks, crime, violence, access to services), historical (i.e. colonialism, Apartheid), political, economic (i.e. poverty, education, class, material deprivation, food insecurity), global (i.e. global economy, power/control) and demographic (i.e. gender, age, ethnicity) factors (Lund et al., 2011; Lund, Stansfeld, & De Silva, 2014; Mills, 2014; Patel & Stein, 2015; Swartz & Rohleder, 2008; Tronto, 2001; WHO & The World Bank, 2011).

2.2 Psychosocial disability

Three concepts are central to the conceptualisation of psychosocial disability, as I shall use it in this dissertation. These are the concepts of disability, mental disorder and stigma. In this

section, I will first describe different models and understandings of disability before I go on to describe major approaches to mental disorder. The overall understanding of disability is central to the understanding of psychosocial disability, as it is conceptualised in this dissertation. Psychosocial disability is understood not just as a clinical diagnosis of a mental disorder, but as a construct at the interplay between a mental disorder, individual characteristics and the social environment. Stigma and prejudice are said to be the greatest barriers to the inclusion of people with disabilities (Groce & Trani, 2009), and thus I will give an introduction to the concept of stigma, related to disability in general and psychosocial disability specifically.

2.2.1 Disability

Disability has always been part of the human condition, and all societies have complex belief systems and practices related to health and disability (Groce, 1999; Gronvik, 2007; Kleinman, 1980; Kleinman & Benson, 2006b; WHO & The World Bank, 2011). Throughout history, people with disabilities have been subject to hatred, curiosity, fascination and sympathy. They have been made exotic, pitied, patronised, ignored and admired (Goodley, 2011). Thus, disability is a complex and contested concept which is in constant flux (Shakespeare, 2015; WHO & The World Bank, 2011), and with no unified definition (Iriarte, 2016).

Historically, a number of different definitions, approaches and understandings of disability have defined the way people with disabilities have been viewed and treated, such as supernatural, spiritual and religious approaches to disability (Braathen, Munthali, & Grut, 2015; Goodley, 2011). A number of models aiming to understand disability have been developed in recent history, including medical (individual), social, minority group, Nordic, affirmative, human rights-based, bio-psycho-social, cultural and other models (Iriarte, 2016). The medical, social and bio-psycho-social models are most commonly referred to, and I will thus concentrate on these. I acknowledge, however, that various other disability models currently exist and are operationalised across and within countries (Iriarte, 2016).

In the biomedical model (also referred to as the individual model) disability is conceptualised as a medical condition, emphasising on impairment (Gronvik, 2007; Iriarte, 2016; Officer & Groce, 2009). This approach offers an individualistic understanding of disability, referring to deficits in the body, something missing in the individual: a limb, an organ or a mechanism in the body (Finkelstein & French, 1993; Harpur, 2012; Iriarte, 2016; Officer & Groce, 2009; Shakespeare, 2014; Shakespeare, Iezzoni, & Groce, 2009).

The past decades have seen a shift from disability viewed as a personal predicament, as in the biomedical model, to disability viewed as a social, cultural and political phenomenon, as in the social model (Goodley, 2011). This model sees disability as a social construct, with physical

and social barriers leading to lack or loss of opportunities preventing people with disabilities from taking part in everyday life on an equal level with others (Finkelstein & French, 1993; Harpur, 2012; Iriarte, 2016; Shakespeare, 2014). While the medical and social models for disability remain the most influential and most debated models for disability, other suggested models have also emerged over the years, such as the tragedy model, the affirmative model, the charity model, the minority group model, the social constructionist model and the relational model (Iriarte, 2016; Shakespeare, 2014). A common characteristic of most of these models is that they have moved away from the individualistic, medical view of disability, towards a view promoting social inclusion for people with disabilities (Shakespeare, 2014).

Researchers have argued that explanatory models for disability have a crucial impact on limiting or ensuring the realisation of human rights for people with disabilities (Braathen et al., 2015; Bricher, 2000; Harpur, 2012; Siminski, 2003). The models provide a starting point for disability related research, practice, theory and everyday living (Chappell, Goodley, & Lawthom, 2001). It has been argued that the medical model is backward looking and reactionary (Shakespeare, 2014), with its lack of emphasis on social factors, discrimination, prejudice and inaccessibility (Officer & Groce, 2009), and as such has contributed to the oppression and marginalisation of people with disabilities (Bricher, 2000; Officer & Groce, 2009; Thomas, 2004). The progressive social model, on the other hand, has been assumed to involve and empower people with disabilities (Bricher, 2000; Officer & Groce, 2009; Shakespeare, 2014; Shakespeare et al., 2009; Thomas, 2004).

Practitioners of scientific medicine[3] have traditionally reinforced, and often continue to reinforce the medical model of disability through their medical practice (Braathen et al., 2015; Bricher, 2000; Gronvik, 2007), emphasising on causes, consequences and treatment of the disabling conditions (Gronvik, 2007; Shakespeare et al., 2009). Rejection of the negative implications of the medical model has however had an unfortunate unintended consequence, to some degree. There has been some defocussing from medical issues as they affect people with disabilities (Shakespeare, 2014). One must not forget that people with disabilities do have health conditions and can often benefit from medical care and rehabilitation. The main limitation to the medical model lies not in its concentration on medical conditions, but rather in its lack of attention to structural issues that contribute to disability and ill health, such as poverty, environmental barriers and social exclusion (Shakespeare, 2014; Shakespeare et al., 2009).

[3] There are many terms used for what I have chosen to call ‘scientific medicine’ in this dissertation. Some use the term ‘biomedicine’, some use ‘western health care’ or ‘western biomedicine’. It is beyond the scope of the dissertation to review the history and usage of all the terms; I use ‘scientific medicine’ because of core claims within this tradition to base treatments on empirical evidence and experimental methods such as clinical trials.

A key limitation to the social model, on the other hand, lies in its lack of attention, at times, to the impact of impairment on disability (Thomas, 2004; Barnes, 2016). As argued by French (1993); "I believe that some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation" (French, 1993, p. 17). Furthermore, Chappell and colleagues (2001) have argued that the social model, with its origin in physical and sensory impairments, to a large extent neglects issues relevant for people with psychosocial and developmental disabilities (Chappell et al., 2001). Adding to this, the social model has been criticised for being too general in its approach to the human experience that disability is, with too little emphasis on the individual, contextual and cultural variations that shape these experiences (Dewsbury, Clarke, Randall, Rouncefield, & Sommerville, 2004; Shakespeare, 2014).

In fact, it has been argued that issues of culture and identity have largely been neglected in all the major disability models (Shakespeare, 2014), and that the models described above, largely developed in the global North, contribute to the marginalisation of the disability experience in the global South (Meekosha, 2011). The cultural perspective, extensively covered in the field of Cultural Disability Studies, tends to move away from the economic questions, while emphasising on the cultural representations of disability. It has been argued, however, that the weakness of this field is that it is too concerned with conceptual issues rather than practical issues, and therefore speaks more to academics than to advocates and policy makers. As a result, it has not been influential on the political disability agenda (Shakespeare, 2014).

All societies have complex belief systems and cultural interpretations related to disability, which are as important in shaping the disability experience as the specific health condition or impairment related to the disability (Groce, 1999; Gronvik, 2007). In many African cultures people base their disability understandings on local knowledge systems, where mental and physical impairments are often attributed to animistic causes, such as witchcraft, ancestors' anger, breaking of taboo or punishment from God (Braathen & Ingstad, 2006; Groce, 1999; Groce & Zola, 1993; Helman, 2007; Ingstad, 1995, 1997, 1999; Ingstad, Bruuns, & Tlou, 1997; Ingstad, Munthali, Braathen, & Grut, 2012; Kleinman, 1980; Munthali, Braathen, Grut, Kamaleri, & Ingstad, 2013; Ross, 2008; Sentumbwe, 1995; Whyte & Ingstad, 1998). Adding to this, disability is sometimes thought to be contagious (Braathen & Ingstad, 2006; Smith, Murray, Yousafzai, & Kasonka, 2004). These beliefs and interpretations lead to assumptions about how individuals with disabilities should be treated and what rights and responsibilities they have (Groce, 1999). In some instances, this leads to people treating disabled individuals in a positive, mythical and elevated manner, or on the other hand in a fearful, disrespectful and excluding manner (Braathen & Ingstad, 2006; Groce, 1999; Whyte & Ingstad, 1998). The treatment is largely dependent on whether the attribute of disability is a valued or a devalued

attribute in that particular setting, context and culture (Groce, 1999). Barnes (2016) argues that while disability is generally seen as synonymous with difference of a negative kind, we must be careful to make such assumptions. Indeed, she argues that disability can also be difference of a positive kind. An extensive body of literature exists on these issues, which is outside the scope of this dissertation. In the sections to follow, however, I will explore traditional beliefs and treatment related specifically to psychosocial disability.

Over the past two decades, an attempt at a more balanced approach to disability has been developed (Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006; WHO & The World Bank, 2011), presented in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001b). ICF conceptualises disability as both a social and medical construct, a dynamic interaction between health conditions and contextual factors; both personal and environmental (WHO & The World Bank, 2011), and as such integrates components of the medical and social model for disability, as well as cultural aspects (Shakespeare, 2014, 2015). This model for disability is known as the bio-psycho-social model (WHO, 2001b). In the World Report on Disability (WHO & The World Bank, 2011), based on ICF, disability is described the following way:

> Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO & The World Bank, 2011, p. 4).

While it has been argued that ICF is theoretically underdeveloped (Shakespeare, 2014), the framework is widely recognised as the definition that best captures all aspects of disability. It highlights the interactive and dynamic nature of disability; acknowledging both individual health status as well as personal and environmental factors in the disability experience (Leonardi et al., 2006; WHO & The World Bank, 2011). The definition is seen as a contributor to equal rights, opportunities and participation in society for people with disabilities (Leonardi et al., 2006).

Because the disability experience is shaped both by the social context as well as by medical conditions, disability is essentially a human rights issue as well as a medical concern (Groce, 1999; Heap, Lorenzo, & Thomas, 2009; Officer & Groce, 2009). All human beings are protected by the Universal Declaration of Human Rights (United Nations, 1948). Despite this, people with disabilities have been, and continue to be, denied many of their basic human rights (Harpur, 2012; Officer & Groce, 2009). In 2006 the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was developed (United Nations, 2006). The purpose of the convention is to "promote, protect and ensure the full and equal enjoyment of all human rights

and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (United Nations, 2006, p. 4). In the convention, disability is defined the following way:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (United Nations, 2006, p. 4).

The convention is perceived by many as a shift in how disability is viewed, and as a major step forward for people with disabilities (Meekosha & Soldatic, 2011). However, while the UNCRPD is based on ICF (Officer & Groce, 2009), it has been argued that the definition of disability adopted by the convention is too medical, restricted to people with long-term impairments, while ignoring level of participation. As a result, the convention risks excluding a vast array of short-term, fluctuating, or episodic impairments (Leonardi et al., 2006). Adding to this, it has been argued that the convention is largely influenced by disability discourses developed in the global North, and as such fails to sufficiently address experiences of people with disabilities in the global South (Meekosha & Soldatic, 2011). For instance, there are well established associations between disability and poverty, poor health outcomes and poor access to health and social services, all of which are far more pronounced and prevalent in the global South than in the global North (Eide & Ingstad, 2011; Elwan, 1999; Groce & Trani, 2009; WHO & The World Bank, 2011). It has been argued that one cannot separate disability from other social and health issues, and that disability issues cannot be appropriately addressed without also considering issues of global power and wealth imbalances (Grech, 2009; Soldatic, 2013).

2.2.2 Mental disorder

Research, treatment and concerns about mental disorders are not new phenomena. Explanatory models and strategies for care and treatment have been present in all societies for thousands of years (Akyeampong, 2015; Cohen, Patel, & Minas, 2014). A number of factors influence the presentation and experience of mental disorders, including notions about what constitutes a mental disorder, availability of resources to diagnose and alleviate mental disorder, culture and beliefs of both patients and carers (Gureje & Stein, 2014). In mental health, as opposed to physical health, it can be difficult to determine when something constitutes a disorder, and when it is within what is considered a "normal" range. Psychological conditions can be within the normal mental range until they start presenting as challenges or barriers to people, at which point they are labelled mental disorders. Mental disorders require some sort of care, management or treatment. Mental health is not a precise science, and as such there is an ongoing debate about whether mental disorders are medical conditions or

moral judgements, and whether the symptoms that constitute the different disorders have cross-cultural validity. These are much debated questions, with no right or wrong answers (Gureje & Stein, 2014). There are several approaches dealing with it, and below I will describe some of the major approaches, and the position taken in this dissertation.

WHO (2010a) defines mental health conditions as including schizophrenia, bipolar disorder, depression, anxiety, epilepsy, dementia, alcohol and drug use disorders, child and adolescent mental health problems and intellectual impairments, among others (WHO, 2010a, 2013b). From the perspective of scientific medicine, diagnosis of a mental disorder is crucial to determine appropriate treatment, care needs, strategies and responses to treatment. Diagnoses should be based on empirical evidence, but while most medical diagnoses are made from biomarkers, these are difficult to find for most mental disorders. Mental disorders are thus usually identified through a number of common symptoms, which at one end of the spectrum are considered normal, and on the other are considered disorders. There is no consensus as to where the cut-off is, and thus diagnosis of mental disorders is not a precise science (Gureje & Stein, 2014).

There are two major classification systems for mental disorders that have international usage and acceptance, namely the Diagnostic and Statistical Manual of Mental Disorders (DSM), currently in its fifth version (APA, 2013), and International Classification of Diseases (ICD), currently in its tenth version (Gureje & Stein, 2014; WHO, 2010b). The DSM, the official classification system of the American Psychiatric Association (APA, 2011, 2013), is the system most commonly used by South African mental health professionals to diagnose and categorise mental disorders. At the time of data collection for this dissertation, DSM IV (APA, 2011) was the latest version of the manual, and the version that was in use by mental health professionals in South Africa. While I recognise that there is now a newer version of the manual (DSM 5) (APA, 2013), for the purpose of consistency throughout this dissertation I will be referring to DSM IV (APA, 2011).

DSM is highly influential in the field of global mental health. And while DSM covers many mental disorders that are recognised as universal, there is also broad acceptance for cultural construction for many conditions described in the manual. It has been argued that this classification system fails to fully account for cultural differences in the expression and experience of mental disorders (Akyeampong, 2015; Patel, 2014). It has also been argued that in many ways DSM conflicts with the World Health Organisation's International Classification of Diseases, and with the more traditional therapeutic practices prevalent throughout the African continent (Akyeampong, 2015). There is, however, an ongoing attempt to improve the cultural sensitivity of DSM through the Cultural Formulation Interview, added to DSM IV and

DSM 5 (APA, 2011, 2013). While the interview is widely used, it has been argued to have many challenges and shortcomings (Aggarwal, Nicasio, DeSilva, Boiler, & Lewis-Fernández, 2013).

Evidence from psychiatric epidemiology from across the world, collected using ICD or DSM, suggests that there are universal elements to mental disorders. However, the World Mental Health Surveys and other empirical evidence have found differences in the prevalence and expression of mental disorders across countries, suggesting that there are contextual and cross-cultural differences (Bass, Bolton, & Murray, 2007; Gureje & Stein, 2014; Kirmayer & Swartz, 2014). Adding to this, the empirical data on mental disorders has been accused of having some problems, such as lack of precision in the tools used and lack of longitudinal studies from LMICs (Gureje & Stein, 2014).

Combining the disciplines of anthropology, sociology, psychology and other related fields, cultural psychology attempts to understand cultural influences on the understanding, prevention, diagnosis and treatment of mental health problems (Cohen et al., 2014; Kirmayer & Swartz, 2014). Two perspectives have dominated this field. The first is that mental disorders are universal biological and psychological processes, referred to as a universalist approach. The second perspective, referred to as a relativist approach, is that experiences of mental disorders are shaped by culture, and that psychiatric disorders are not universal in nature (Cohen et al., 2014).

At the core of universalism is the assumption that psychological concepts are universal constructs, and hence can be found transculturally. Universalist approaches primarily utilise quantitative research methods, using scales presumed to measure universal constructs (Cohen et al., 2014; Gureje & Stein, 2014; Swartz & Rohleder, 2008). Swartz and Rohleder (2008) argue that this approach places Western psychology on top of a pyramid, where superior Westerners supposedly know and understand the "real" phenomena, which, although clear in Western culture, are hidden by the cultural practices in other cultures. Furthermore, they argue that in this approach the psychological and emotional worlds of Westerners are seen as superior to that of other cultures, and other cultures are seen as developing towards the superior level of Western culture. They argue that in the field of mental health Western diagnostic systems are often used as a standard to represent syndromes that manifest across all cultures, only with some variation (Swartz & Rohleder, 2008).

Relativism is the approach of many proponents of cultural psychology. This approach sees different cultures as separate with few comparative measures. Context is seen as crucial to psychological phenomena, and hence universal meanings cannot be extracted from data without referring to context. Ethnography is a commonly used method in relativist understandings of the world (Cohen et al., 2014; Swartz & Rohleder, 2008).

The critical approach to mental disorder is the approach taken by many within the movement for global mental health, and by some critics of this movement (Mills, 2014; Swartz, 2012). The approach is a combination of the universalist and relativist approach. The critical approach claims that rather than one standard psychology, there are multiple, diverse psychologies. This approach attempts to make sense of the diversity, without denying universals, arguing that all contexts have multiple and diverse cultures and thus psychological concepts must be understood with a critical understanding of diversity and how knowledge is produced. The core of this approach is that while there are differences in the expression of and responses to mental disorders, these disorders are present in all cultures and societies, and that there are questions of power and resources in terms of who is permitted to name and intervene with mental disorders (Cohen et al., 2014; Gureje & Stein, 2014; Patel, 2012; Swartz & Rohleder, 2008). A key factor, then, in a critical approach to mental disorder is that it views issues of difference and diversity in the experience and expression of psychological phenomena as linked to broader social phenomena of power and control, such as colonialism, the global economy and the economic power of multinational drug companies (Swartz & Rohleder, 2008). While many scholars in the field of global mental health are proponents of a critical approach to mental disorder, Mills (2014) accuses the movement of still placing too much emphasis on the biological aspects of mental disorders, and too little on the historical, global, political and economic contexts in which they occur. She argues that these contextual factors, from which many mental disorders emerge, must not be undermined, but that they must be addressed in order to respond appropriately to mental disorders (Mills, 2014).

Scientific medicine and psychiatry are cultural institutions, influenced by their history and values. Psychiatry has been accused of seeing mental disorders primarily as brain disorders, located within an individual because of a dysfunctional biology or psychology. From this perspective, psychiatry first and foremost searches for biological explanations for mental disorder and uses psychopharmaceuticals as treatment. There is, however, limited evidence to support the claim that mental disorders can be attributed to brain dysfunctions alone. Mental disorders are also rooted in social-developmental processes; interactions in the local social environment, including family, community and other networks. Thus, effective interventions to prevent and treat mental disorders must understand and address these interactions (Kirmayer & Swartz, 2014). The social determinants of mental disorders make them different from other illnesses. Social factors are crucial in determining mental health status, in interaction with genetic and individual factors. Social factors can be, for instance, poverty related factors, such as income, education, class, material deprivation and food insecurity; demographic factors, such as gender and ethnicity; and environmental factors, such as crime, violence, living in a poor area, access to health and social services, natural disasters, war and conflict.

Understanding these social factors can contribute to making population-level interventions more effective and efficient (Lund et al., 2011; Lund et al., 2014; Patel & Stein, 2015). While some studies have suggested that there is a direct relationship between mental disorder and poverty (Corrigall, Lund, Patel, Plagerson, & Funk, 2008; Lund, Breen, et al., 2010; Lund et al., 2011; Lund et al., 2014), others have argued that this relationship is less pronounced (Das, Do, Friedman, McKenzie, & Scott, 2007, 2008). The specifics of this debate is outside the scope of this dissertation, which looks at mental disorder in the context of poverty, without studying the question of the causal relationship between mental disorder and poverty.

It is widely recognised that culture is closely connected with mental health. Our ability to function as human beings is influenced by culturally shaped systems of meaning (Kirmayer & Swartz, 2014). Culture and mental disorder are linked in a number of ways. Culture impacts on the prevalence of mental disorder, aetiology and course of mental disorder, phenomenology and expression of distress, diagnostic and assessment issues, coping styles and help-seeking pathways, and treatment and intervention issues (Hwang, Myers, Abe-Kim, & Ting, 2008). In psychiatry, culture can be used to assist with patient-communication, provider interpretation, for health planners to understand determinants for health seeking/coping/response and for researchers to understand the role of culture in mental disorder and treatment. Culture plays a central role in shaping local explanations of mental disorder, which shapes knowledge and practice, and thus the experience of mental disorders (Bass et al., 2007; Kirmayer & Swartz, 2014). Culture is socially constructed and expressed by humans, a system of symbols and values of different social groups and communities. It is local, belonging to a group or community, and global, across communities and societies. It can be used to refer to religious groups, tribes, ethnicity, geography, occupation or other social characteristics of humans (Kirmayer & Swartz, 2014). There is a large field of research trying to define and measure cultural variation in psychology, both across and within countries and contexts (cross-cultural psychology) (IACCP, 2016; Lonner, 2000), but this is outside the scope of this dissertation. The fact remains that culture is difficult to measure accurately in large cross-national epidemiological studies, and is thus often reduced to geographic location. There is, however, cultural variation within most geographical locations (Bass et al., 2007; Kirmayer & Swartz, 2014).

Many scholars believe that many symptoms of mental disorders are universal, but their content varies, and as such, it is crucial to apply a bottom-up approach to achieve culturally relevant descriptions of mental disorders. The relevance of diagnostic tools such as the DSM in an African context has been questioned. Assuming that it is not a valid tool in these contexts, it follows that the appropriateness of the psychiatric response to many mental disorders can also be questioned (Patel & Stein, 2015). In traditional African medicine, mental disorder is

commonly understood as a person interpreting reality in an unusual way, unable to separate reality from fantasy, with a dysfunction of the senses. Many traditional healers believe that there are spiritual aspects to mental disorders, and that these patients are protected against evil forces such as spells or bewitchment. On the other hand, many healers also believe that mental disorder can be caused by spiritual forces such as witches, wizards, sorcerers and demons, often as punishment for wrong-doings by the person him or herself or by their parents. As such, the management of mental disorders by traditional healers is very different from the way they are handled by scientific medicine (Okello & Musisi, 2015).

There is no such thing as one homogenous Black African or amaXhosa experience of mental disorder. Constructions of mental disorder are closely linked to the social, cultural and religious context in which people live, and is thus highly context specific (Bartholomew, 2016; Kleinman, 1980, 1988; Lund & Swartz, 1998; Sorsdahl, Flisher, Wilson, & Stein, 2010). In many African societies traditional beliefs and prejudices form the basis for experiences of attitudes towards mental disorder (Bartholomew, 2016; Botha, Koen, & Niehaus, 2006; Egbe, 2015; Mavundla, Toth, & Mphelane, 2009). However, many mental disorders present with the same symptoms in most cultures. For common mental disorders (CMD), referring to depressive-, anxiety- and somatoform disorders (physical complaints with no obvious physical cause), patients commonly report the somatic symptoms, such as tiredness, sleep disturbance, aches, pains and dizziness. However, when asked, they will also commonly report psychological symptoms, such as loss of interest, suicidal thoughts, lack of concentration, anxiety and worry. The somatic symptoms are more commonly reported unasked, while the psychological symptoms are generally reported on inquiry. In studies from Africa, culture specific symptoms of CMD have been reported, such as thinking too much, feelings of heat or pressure in the head and feelings of something moving under the skin (for instance, insects) (Patel & Stein, 2015; Tomlinson, Swartz, Kruger, & Gureje, 2007). *Kufungisisa* is a cognitive experience described in many African countries. It is described as a combination of worrying and obsessive thinking, which are universal phenomena, but the specific experience of *kufungisisa* is highly cultural. Similarly, when patients describe symptoms of feelings of ants or insects crawling under their skin, this can be diagnosed as hallucination, or it can be associated with the tingling numbness associated with hyperventilation, often experienced by people who are anxious (Patel & Stein, 2015). In Uganda, researchers found that depressive symptoms were described as "thinking too much", as opposed to sadness, which is more common in Western societies. As such, people in Uganda generally see nonpsychotic depression as an illness of thoughts, caused by worrying about psychosocial problems. This illness was not perceived to require scientific medicine, but rather something that could be solved with the help of the patient's social support system of family, friends, religious groups, elders, traditional healers and others. Depression

with psychosis, on the other hand, was believed to have been caused by bad relationships between the living and the dead. Dealing with the bad relationship was seen as the best way to manage this type of depression, a process involving a traditional healer, the patient and sometimes other members of the clan involved in ancestor worship (Okello & Musisi, 2015). *Amafufunyana* is a cognitive experience commonly referred to among Black African patients in a South African context, and among isiXhosa-speaking people in general. Some patients who experience *amafufunyana* are diagnosed with depression by psychiatry, others are diagnosed with schizophrenia (Patel & Stein, 2015), while others again are labelled psychotic (Mzimkulu & Simbayi, 2006). *Amafufunyana* has been described as a set of symptoms, such as hysteria, nerves, weeping, violent and aggressive behaviour towards self and others, suicidal attempts, delusions, hallucinations and disorientation. It has also been described as an explanatory model to make sense of these symptoms, which includes explanations of spirit possession due to sorcery or witchcraft. While patients are commonly diagnosed with schizophrenia or depression, they rarely associate with these disorders themselves, but ascribe to mystical/spiritual explanatory models, such as *amafufunyana*. Despite this, it has been found that many patients who ascribe to the more mystical/spiritual explanatory models report that they benefit from psychiatric medication, which is also the preferred mode of treatment for many. Thus, many patients employ traditional and scientific/biomedical explanatory models and modes of treatment simultaneously. Psychiatric treatment is noted by many to remove the symptoms and provide patients with better functioning, but does not necessarily provide a plausible explanation for the symptoms. The more traditional explanatory models, on the other hand, have been said to be useful in removing the blame from the patients, and thus reducing stigma (Lund & Swartz, 1998; Mzimkulu & Simbayi, 2006). Similarly, *ukuthwasa*, a condition described as very similar to *amafufunyana* in Xhosa traditional healing, bears resemblance to the DSM condition described as schizophrenia. *Ukuthwasa* is reported by many patients to be genetic; that is there is often a family history of the condition. Interestingly, *ukuthwasa* seems to have more positive connotations and less associated impairment compared to *amafufunyana*, which is viewed more negatively and results in serious impairments (Niehaus et al., 2004). Ancestors and witches have been described as unconscious components of the human psyche. Relationship to ancestors is generally positive, while relationship to witches is negative. *Ukuthwasa* has been described as the process through which a person is called by ancestors to receive training and become a traditional healer, and thus work as a link between ancestors and the living. During this process the person experiences symptoms of mental disorder similar to schizophrenia. Bewitchment, on the other hand, is understood as misfortunes; illness, destruction or even death, caused by evil intentions by witches. Bewitchment only happens to people who, for some reason, are not protected by ancestors. This could be because they have offended the ancestors through

disrespectful behaviour or neglecting ancestor customs. People who have been bewitched commonly express symptoms of anxiety, fear and depression. Symptoms of *ukuthwasa* and bewitchment resonate both with scientific biomedical diagnostic systems and with traditional Xhosa diagnostic systems (Bührmann, 1982; Sorsdahl et al., 2010). Among Black South Africans, epilepsy is another condition which is commonly explained through sociocultural, psychological, economic and political explanatory models. While traditional explanatory models for severe and more common mental disorders vary, it remains important to keep cultural and contextual factors at the core of understanding and responding to mental disorder. It is more complex than simply understanding mental disorder in a scientific medicine way OR a traditional way. Individual, contextual and cultural realities must be explored and understood, and integrated into strategies to manage mental disorders (Keikelame & Swartz, 2013a).

As described above, it is often asserted that African patients with mental disorders commonly seek and prefer supernatural explanations (witchcraft, ancestors, God) for these disorders, while patients from Western countries generally prefer psychiatric explanations. However, throughout the world patients commonly seek multiple explanatory models, however contradictory, concurrently (Brooke-Sumner, Lund, & Petersen, 2014; Patel & Stein, 2015; Tomlinson et al., 2007).

Thornicroft (2006) describes three major approaches to mental disorders, namely the biomedical model (problem is within the individual), the individual growth model (continuum between emotional well-being and ill health) and the disability-inclusion model (main problem is with how society reacts to the mental disorder). The latter is described as the most appropriate, and the most useful model for purposes of reducing stigma and discrimination, and thus increasing inclusion and quality of life for people with mental disorders (Thornicroft, 2006). The association of mental disorder with disability is multidirectional. On the one hand, disability is seen as separate from, and merely a consequence of, the mental disorder, and on the other hand, disability is seen as part of the mental disorder, which can be used to describe the severity of the disorder (Andrews & Titov, 2007; Gureje & Stein, 2014; Patel & Stein, 2015; Prince et al., 2007). Disability ". . .is sometimes used to connote activity limitations that may be associated with a particular mental disorder and sometimes as a way of describing the severity of a mental disorder" (Gureje & Stein, 2014, p. 31). The rights of people with mental disorders are increasingly seen within a human rights framework; most relevant is the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), described above (Kirmayer & Swartz, 2014; United Nations, 2006).

2.2.3 Stigma

> . . .throughout history, socioeconomic status has had a robust association with disease and death: people with greater resources of knowledge, money, power, prestige, and social connections are generally better able to avoid risks and to adopt protective strategies. As stigma places people at a substantial social disadvantage with respect to these resources, it increases their exposure to risks and limits access to protective factors, potentially adding to their burden of disease or disability (Link & Phelan, 2006, p. 529).

The concept of stigma is central to social science in general, and to the fields of disability and psychosocial disability in particular. Stigma is often used as a broad term to include issues of ignorance, discrimination, prejudice, labelling and stereotyping (Phelan, Link, & Dovidio, 2008; Thornicroft, 2006; Wahl, 2012). It is a big part of the overall experience for people living with chronic health conditions, such as psychosocial disability (Egbe, 2015; Engebretson, 2013), and the experience of stigma is often described as being worse than the main condition (Thornicroft, 2006). Adding to this, stigma represents a major barrier to health and social services for many people with disabilities (Egbe et al., 2014). Thus, stigma theory is an important aspect in the exploration of care in relation to people with psychosocial disabilities. While stigma is a universal phenomenon, in the sense that it occurs in all contexts and cultures, it is increasingly recognised that the specifics of the stigma experience and discrimination associated with it is highly localised (Coleman, 1997; Kleinman & Hall-Clifford, 2009; Parker & Aggleton, 2003; Schierenbeck, Johansson, Andersson, & van Rooyen, 2013; Yang et al., 2007). To combat stigma, it is essential to understand the localised social and cultural processes that create stigma (Kleinman & Hall-Clifford, 2009). Despite this, the majority of the evidence and research on stigma is from high-income countries, with a scarcity of evidence from LMICs (Thornicroft et al., 2016). This section on stigma will describe briefly the major developments in stigma theory over the past 50 years, with a primary emphasis on how it relates to psychosocial disability. I will not go into depth on the extensive theoretical and empirical literature that exists in the field.

One of the earliest and most influential works in the field of stigma is Goffman's book "Stigma: Notes on the management of spoiled identity" (Goffman, 1963). Goffman defines stigma as a discrediting attribute, which occurs in the gap between an individual's virtual social identity and actual social identity. Stigmatised people possess undesirable characteristics that are not within the normal characteristics in the category they belong to. These people are thus reduced in people's minds from whole and normal people, to tainted, discounted ones (Goffman, 1963). Processes of social construction are central to Goffman's argument. Stigma, based primarily

on first impressions, occurs through mixed social contacts between stigmatised people and people who are considered normal. People's anticipation of others is largely based on these first appearances (Goffman, 1963, 1997). Goffman (1997) describes three types of stigma: First, abominations of the body, such as physical deformities; second, blemishes of individual character; and third, tribal stigma, referring to race, nationality and religion (Goffman, 1997). He distinguishes between people who are discredited and people who are discreditable. A discredited person is someone whose differences are evident on the spot, while a person who is discreditable possesses undesirable attributes that are not immediately perceivable to those present. Some attributes, positive or negative, are really possessed by an individual, others are only perceived, but not real, attributes of the individual. Stigma occurs at the discrepancy between perceived and real attributes (Goffman, 1963). Goffman (1963, 1997) argues that normality is the counterpart to stigma, but he has been criticised for not explaining what normality is or how it is constructed (Davis, 1997). Davis (1997) argues that we live in a world of norms, of average people, where we aim to be normal, or deliberately try to avoid being normal. To understand disability stigma, he argues, one must return to the concept of normality, and the normal body. He states that ". . .the problem is not the person with disabilities, the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person" (Davis, 1997, p. 9).

A person who is stigmatised is often seen as a victim, inferior, and someone who is not quite human (Goffman, 1997). Goffman describes a dilemma for "normals" in how they should treat a stigmatised person. The dilemma lies in finding a balance between making impossible demands where the stigmatised person has a shortcoming, and on the other hand facilitating full participation for these individuals. These situations can make some sort of secondary gain for stigmatised people, in that they can escape from the responsibilities of normals, hiding behind their stigma (Goffman, 1997).

One criticism of Goffman’s notion of stigma is that his argument implies that stigma is a static and fixed concept (Coleman, 1997; Parker & Aggleton, 2003). Contrary to this, Coleman (1997) argues that stigmas mirror culture and society, and that they are in constant flux, representing ". . .a view of life; a set of personal and social constructs; a set of relations and relationships; a form of social reality" (Coleman, 1997, p. 216). While Goffman (1997) argues that certain characteristics are undesirable and abnormal, and others are normal, Coleman (1997) argues that these notions are culture bound. What is normal and desirable differs between and even within cultures. It is the dominant group in a given context that sets the standards for which human characteristics are seen as desirable and undesirable (Coleman, 1997). Similarly, Parker and Aggleton (2003) argue that stigma, constructed through interaction, is a social

process, which operates in relation to difference and also in relation to social and structural inequalities (Parker & Aggleton, 2003).

Since Goffman's (1963) early work on stigma, the definitions and theoretical models have evolved from an individualistic focus towards emphasis on the social aspects of stigma (Yang et al., 2007). Empirical research on stigma has primarily focused on individual and psychological aspects, while neglecting the local, social and relational aspects of stigma (Kleinman & Hall-Clifford, 2009). Anthropological contributions to the field of stigma have introduced the notion of stigma as a moral issue (Kleinman & Hall-Clifford, 2009; Yang & Kleinman, 2008; Yang et al., 2007). From this perspective stigma is shaped at the interaction between structural discrimination and cultural engagements (Yang et al., 2014). Stigma is seen as a social process, where "stigmatized conditions threaten what is at stake for the sufferers" (Yang et al., 2007, p. 1524). This is referring to everyday life activities and experiences that matters the most to people, and the moral experiences are the things that threaten to diminish or destroy these (Yang et al., 2007). From this point of view, the stigmatised individual is seen as a person with a moral status, which is determined by their ability to meet social obligations and norms in the particular local social world they inhabit. Stigmatised individuals are often not able to meet these obligations, and as such are unable to obtain the things that matters the most to many people, such as wealth, relationships and life chances (Kleinman & Hall-Clifford, 2009).

Link and Phelan (2006) propose a model for stigma which includes structural discrimination. They conceptualise stigma as "the result of a process in which a series of five interrelated components combine to generate stigma" (Link & Phelan, 2006, p. 528). The first component is the way people identify and label human differences, and whether differences are considered relevant and consequential or not. The second component of stigma refers to stereotyping, linking the stigmatised individual to undesirable characteristics. The third component is about separating "them", the stigmatised, from "us", those stigmatising. Fourth, due to the labelling, being linked to undesirable characteristics and being set apart from the stigmatising group, a rational emerges for the devaluation, rejection and exclusion of the stigmatised. Finally, the fifth component of stigma is the exercise of power (Link & Phelan, 2006). They describe three forms of discrimination; direct discrimination (direct, open, from one party to another), structural discrimination (subtler, less direct, stem from institutional/social structures) and insidious discrimination (stigmatised individual's expectations of other people's expectations to them, and acting to confirm or reject these believed expectations) (Link & Phelan, 2006). Phelan and colleagues (2008) describe three ways stigma is commonly exercised; namely exploitation and domination (keeping people down), norm enforcement (keeping people in) and disease avoidance (keep people away) (Phelan et al., 2008). Coleman (1997) argues that three

universal aspects are present where stigma is present. The first aspect is fear, which is stigma's primary affective component; people are afraid of the unknown, and act accordingly. The second aspect is stereotyping, which is stigma's primary cognitive component; a way of rationalising the unknown. The third aspect is social control, which is stigma's primary behavioural component; our actions towards stigmatised individuals (Coleman, 1997). Stigma promotes group cohesion and safety (Engebretson, 2013). In addition to the stigmatisation by "others" described above, and referred to as externally imposed stigma, those who are stigmatised often internalise the stigma, or perceive stigma in a process of self-stigma (Engebretson, 2013; Wahl, 2012; Yang et al., 2014). Stigma can result in stereotyping, separation, isolation, lack of social status, discrimination (Engebretson, 2013), decreased self-esteem, reduced access to health and care, and more (Sartorius, 2007).

Stigma is usually imposed on a person by someone who does not possess the same stigmatising attributes themselves, and it is closely linked to ignorance and misinformation. It is an attack on a person's identity, integrity and reputation (Thornicroft, 2006). Stigma can also be imposed on friends or family members associated with the individual who possesses the undesirable characteristic, referred to as stigma by association (Thornicroft, 2006). The best way to combat stigma is through social interaction with stigmatised individuals. Thornicroft (2006) describes mental health stigma as made up of three components, namely ignorance (related to knowledge), prejudice (related to attitudes) and discrimination (related to behaviour). In order to tackle stigma one must develop interventions that address these problem areas (Thornicroft, 2006).

For psychosocial disability, it has been argued that language can create labels, which in turn can be stigmatising. An example of a language label is the use of a derogatory and labelling term such as "he is a schizophrenic", instead of saying "he has schizophrenia". The latter refers to a person with an illness, as opposed to the person embodying the illness in the first term (Howell, Ulan, & Powell, 2014; Rose, Thornicroft, Pinfold, & Kassam, 2007; Sartorius, 2007). Such labels are associated with stigmatising attitudes, essentialist thinking and lower empathy (Howell et al., 2014). Adding to this, it has been argued that the stigma attached to psychosocial disabilities is a major obstacle for both care-seeking and provision of care to these individuals, and the main obstacle to successful programmes to improve mental health (Rose et al., 2007; Sartorius, 2007; Thornicroft, 2006). Stigma applies not only to individuals with psychosocial disabilities, but also to their families, institutions, individuals and treatments that care for people with psychosocial disabilities (Sartorius, 2007). Stigma in relation to psychosocial disability is defined as "the negative attitude (based on prejudice and misinformation) that is triggered by a marker of illness – e.g., odd behaviour or mention of psychiatric treatment. . ." (Sartorius, 2007, p. 810). People with psychosocial disabilities are

often the objects of indirect stigma (Wahl, 2012), or seen as, what Goffman (1963) refers to as, discreditable. Their disability is often not immediately visible or obvious, but the characteristics associated with their disability are usually seen as undesirable (Wahl, 2012).

Studies have found associations between experienced discrimination and elevated risk for mental disorder (Moomal et al., 2009). Studies from South Africa have found that the association is stronger for non-racial than for racial discrimination. Mostly the risk is more pronounced for chronic than for acute discrimination, except for racial discrimination, where acute discrimination has stronger associations with mental disorders than chronic discrimination. This could be because unexpected and unpredictable stressors have stronger associations to mental disorder. In a South African context, racial discrimination has existed for many decades, and people may have become accustomed to, and thus not as affected by it (Moomal et al., 2009).

2.3 Care

> People do not spring up from the soil like mushrooms. People produce people. People need to be cared for and nurtured throughout their lives by other people, at some times more urgently and more completely than at other times (Kittay, Jennings, & Wasunna, 2005, p. 443)

Care is a widely used and debated concept in research; highly contextual and difficult to define. It is usually conceptualised as a practice or virtue, rather than a theory, with the overall aim of care being to maintain the world by meeting the needs of ourselves and of others (Sander-Staudt, 2011). Care is an essential human practice, crucial for individual survival, as well as the survival of societies, as argued by Kittay (1999, in Engster 2005); "If no one cared for others, society would cease to exist within a generation or two" (Kittay 1999, in Engster, 2005, p. 60). Over the past decades several different, but overlapping, definitions of care have emerged (Sander-Staudt, 2011) and have been applied to areas ranging from nursing to economics (Anderson & Turner, 2010). Central to this dissertation are the fields of care ethics, anthropological/cultural approaches to health care and occupational participation as care. From the ethics of care literature, I have found the thinking of Tronto (Fisher & Tronto, 1990; Tronto, 1993, 2001, 2010) particularly relevant, but I will also draw upon the works of other scholars such as Kittay (Kittay et al., 2005) and Engster (2005). I have also found anthropological approaches to pluralistic health care, as brought forward by Helman (2007), Kleinman (1980) and Janzen (1978), relevant. From the fields of disability and occupational therapy, I have found the paradigms connected to occupational participation as a way of caring, to be relevant. Finally, in the area of care for people with psychosocial disabilities, the field of

Global Mental Health has been particularly influential over the past decade. These fields will be described below.

2.3.1 Ethics of care

> . . .care ethics seeks to maintain relationships by contextualising and promoting the well-being of care-givers and care-receivers in a network of social relations (Sander-Staudt, 2011, p. 1)

Feminist ethics has historically been related to the ethics of care field. Ethics of care emerged largely from the study of activities and virtues associated with mothering, but have more recently expanded to include other relationships, like friendship and citizenship (Sander-Staudt, 2011). While there are many parallels between care ethics and feminist ethics, these fields are not the same. In popular thinking people tend to think of certain races, ethnicities, classes and genders as possessing caring and non-caring attributes, and as such the practice and virtue of care is thought of as having many feminine traits, but not all feminist ethics are care ethics, and not all care ethics are feminist. Still, ethics of care is usually thought of as a theory rising from feminist scholars, but the uniqueness of the theory lies in its emphasis on social power, identity, relationships and interdependency (Sander-Staudt, 2011). Ethics of care is a relational theory that sees human beings not as isolated entities, but as dependent and interdependent beings (Kittay et al., 2005).

The concept of care ethics as a moral theory was introduced by the psychologist, Gilligan (1982) and the philosopher, Noddings (1982) in the 1980s (Sander-Staudt, 2011). The theory has been further developed by other influential scholars such as Held (1993, 2006), Kittay (1999; Kittay et al., 2005; Kittay & Myers, 1987) and Tronto (1993), amongst others. I will not describe in detail the thinking of all these scholars, but will focus on issues that I have found particularly relevant to this dissertation. I will primarily focus on the theories developed by Tronto (Fisher & Tronto, 1990; Tronto, 1993, 2001, 2010, 2013), who presents a contextual and political approach to an ethics of care. I have also found some of the work by Kittay (Kittay et al., 2005) and Engster (2005) to be particularly relevant. These are described below.

Tronto

Care is often thought of as private, something that happens in homes, usually a woman's domain, but Tronto (2001, 2013) argues that care can be both private and public. As caring practices are commonly performed by women, and women are seen as better carers, Tronto argues for a larger overlap between care and feminist theories (Sander-Staudt, 2011). Fisher and Tronto (1990, cited in Tronto, 1993, 2010) propose a view of care as a human practice,

rather than as a disposition. They describe optimal care as an integral and holistic process that involves taking the needs of others as a basis for action. They state:

> On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue and repair our “world” so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web. (Fisher and Tronto, 1990, in Tronto 1993, p. 103)

Tronto and Fisher's (1990, cited in Tronto, 1993, 2010) definition of care, refined by Tronto (1993), is one of the most popular and widely used (Sander-Staudt, 2011). Adding to this early definition of care, Tronto (2001) states that "we care so that we can live in the world as well as possible" (Tronto, 2001, p. 61). She proposes four phases of care, and good care, she argues, is an integration of these four phases (Tronto, 1993). The first phase is caring about, referring to recognizing a need for care. The second phase is caring for, which is taking responsibility to meet the recognized need. The third phase is care giving, the physical work of providing care. And finally, the fourth phase is care receiving, which is referring to the evaluation of how well the care provided has met the need for care. Linked to these four phases, Tronto (1993, pp. 126-137) describes four emerging sub-elements of care:

1. Attentiveness: being attentive to other's needs/being aware of need.
2. Responsibility: a willingness to respond and take care of need.
3. Competence: the skill of providing good and successful care (including availability of necessary resources).
4. Responsiveness: of the care receiver to the care; consideration of the position of others as they see it and recognition of the potential for abuse in care.

While ethics of care has largely been seen as a feminist discipline, Tronto (1993) argues that it is first and foremost a moral theory. Although the concept of care is commonly closely related to female attributes and charged with gender differences, too much emphasis on care as primarily an issue of gender could reduce the validity of the theory (Tronto, 1993). Furthermore, Tronto argues that both men and women should be responsible for care and care ethics in the private and public domain (Tronto, 1993, 2013). Tronto's thinking has pushed the ethics of care discipline into a political discourse, and provides a contextual approach, recognising that access to care and the provision of care is dependent on the social, relational, economic and political context in which care takes place. Hence, care should be understood as being a highly flexible concept, and what is seen as good care is dependent on people's way of life, their culture and their values (Tronto, 2001, 2013). Tronto (2001, 2013) argues that care happens at all levels of society; in the household, in the marketplace, in institutions, in governments and

so on. Tronto's definition of care has been praised for its consideration to cultural variation, and how it extends beyond the family and domestic spheres. On the other hand, the definition has been criticised for being too broad, seeing nearly all human activities as care (Sander-Staudt, 2011).

Tronto (1993) highlights two dangers in the provision of care, namely paternalism and parochialism. Paternalism is when the care giver assumes to know better than the care receiver what his/her care needs are. Parochialism refers to care givers' preference for care receivers who are close to them.

In the context of care institutions, some scholars have argued that the best way to determine the quality of care is to use family care as a model, and that a good caring institution should run more like a family than a bureaucracy (Tronto, 2010). Contrary to this thinking, Tronto (2010) argues that despite some similarities, there are distinct differences between family care and institutional care. All forms of caring understood as a relational practice should include three principles:

1 Attention to politics and relations of power.
2 Particularity and plurality; the realisation that activities are particular and that there are multiple ways of doing them based on diverse human preferences.
3 Awareness about the purpose of care from the different perspectives of those involved in the care activity.

Family care is commonly automatic, resting upon clear lines of power and obligation, highly particularistic to each individual and each family. Institutional care, on the other hand, is primarily turned towards the market and focussed on effectiveness measured through customer satisfaction and competition. In an institutional setting, approaches to purpose, power and particularity are often conflicting, and to ensure that the institutions meet their caring obligations they need to create space for continuous evaluation of their pursuits of purposes, their coping with particularity and how power is used within the organisation (Tronto, 2010). Tronto (2010) problematizes measuring care through customer satisfaction and competition. She questions whether customer satisfaction is a suitable measure for good care, as it is based on market assumptions about the customer. These assumptions see the customer as someone who is rational, autonomous and capable of making an informed choice, characteristics that are often not true of a "care customer". Furthermore, Tronto (2010) argues that while competition may be useful in determining which service provider is better than another, this is not very useful in determining the overall quality of care. The best care institutions, Tronto (2010, 2013) argues, are those that focus on outcome, rather than profit, and those that recognise all those involved in the organisation of care, from the care customers

to the care workers. All of these people should share a common purpose and the best way of reaching this purpose. Tronto (2010) describes seven warning signs of institutions that are not providing good care:

1. The first warning sign is institutions based on the assumption that misfortune, vulnerability and dependency cause the need for care. Tronto (2010) argues that all human beings require care all the time, but different kinds of care in different phases of their lives.
2. The second warning sign is institutions taking needs as given and fixed within the organisation. Institutions failing to recognise the fluctuating, contextual and individual nature of needs are likely to inflict more harm than good in trying to meet these needs.
3. Third, institutions considering care a commodity, rather than a process, are likely to become alienating, focussing more on the market and profit than on meeting actual needs.
4. The fourth warning sign is when care receivers are seen as incompetent and dependent, and hence lacking of expertise with regards to their own needs.
5. Fifth, care institutions failing to understand the full process of care, including both care attentiveness and care responsibilities, are unlikely to successfully meet care needs.
6. The sixth warning sign refers to organisational requirements that function as hindrances to, rather than support for, care.
7. The seventh warning sign is care being seen as having secondary status in society, being the work of less well-off and more marginal groups in terms of caste, gender and race

Most caring institutions today treat people in standardised ways, providing care for people who are described and treated as vulnerable and incompetent (Tronto, 2010). Tronto (2010) argues that determining needs is complicated, as needs change over time, for particular individuals, as medical techniques and interventions change and as societies, contexts, culture and politics change. In such a reality, caring institutions must have a continuous rhetorical, moral and political space for interpreting and determining needs. Furthermore, institutions must consider needs and perspectives of all those involved in care activities, both care receivers and care givers, within the institution. Tronto (2010) states that, "Non-family care can be outstanding in its quality, but only if organisations that provide care also care about their own ways of working" (p. 169).

Characteristics of ideal caring, as described by Tronto (2010), are care without prejudice for race, gender, sexual orientation and so on. Furthermore, she argues that caring work should be well paid and flexible in terms of various systems and providers for meeting needs. She

rejects the notions of a standardised model for care, and proposes a model that depends on people's sensibilities and real needs.

Kittay

Kittay has long standing as a philosopher, but it is her more recent work that is most clearly applicable to the current study, particularly her article entitled "Dependency, Difference and the Global Ethic of Longterm Care" (Kittay et al., 2005). Similar to Tronto, Kittay and colleagues (Kittay et al., 2005) sees both providers and receivers of care as dependent on social and political organisation, dictated first and foremost by human need, but also by cultural, ethical, contextual, economic and political circumstances. They see care as a practice and a value, rather than a virtue, arguing that we must not lose sight of care as work (Sander-Staudt, 2011). They argue that distribution of care is a question of justice, while the interaction between care giver, receiver and the wider community is a matter of ethical inquiry. Central to the ethics of care theory are the power relations between the care giver and the care receiver, as care is seen as inevitably linked to dependency. Kittay and colleagues (Kittay et al., 2005), however, distinguish between care and dependency care, where care is broader, and can also include services people are able to provide for themselves, but choose not to. Dependency care is described as services a person is unable to do for him/herself, and hence in dependency care the person in need of care is inevitably dependent because s/he is too young, too ill or impaired, or too frail to manage self-maintenance alone. Kittay and colleagues (Kittay et al., 2005) describe care as a labour regardless of whether it is paid for or not. While care is a hands-on activity, it can also be taking the responsibility of supervising or financially supporting hands-on care work. They argue that despite variations and differences, there are some universal aspects to the meaning and experience of care. First, they argue that all care involves an intimate relationship between two or more people, and the caring affects all parties involved in the care activity. Furthermore, they describe care as a relationship that occurs in a psychological and social context, deeply dependent on cultural and ethical meaning, which in turn shapes the experiences of the participants. On an individual level Kittay and colleagues (Kittay et al., 2005) describe care as personal, social, symbolic, meaningful, emotional, rational, pragmatic and practical. There are major differences across the world as to what constitutes good care, about who is responsible for providing care and to whom. These differences are linked to differences in social traditions, family systems, gender roles and cultural worldviews. Kittay and others (Kittay et al., 2005) argue that "a care ethics, with its emphasis on attention to the other and the importance of context in moral decision-making, is useful for orienting us toward cultural difference. In its emphasis on the importance of relationships, it is an ethic that may resonate well with less individualistic societies than our

own" (p. 464). They further argue that it is important to respect differences in the ways care activities are performed, as long as they promote human flourishing.

A challenge to the construction of good care is what Kittay and colleagues (Kittay et al., 2005) refer to as the politics of sameness. This politics is one that does not consider differences in values regarding dependency and care. The politics of sameness, they argue, is oppressing, especially to the most disadvantaged groups who benefit the least and are burdened the most by this approach to care. Kittay and colleagues (Kittay et al., 2005) argue for the benefit of forming alliances between individuals and groups with similar needs, while at the same time acknowledging different and conflicting needs within such alliances. One must be careful not to assume that people have the same needs, interests and situations, on the contrary, structural, social and individual differences should inform a global ethics of long-term care. Kittay and colleagues (Kittay et al., 2005) state that a dream society is "…one that recognises commonality and respects difference" (p. 469). They list a number of inequalities and differences commonly found across and within societies; inequalities of power and wealth, differences in ways people live their lives and disadvantaged groups. Disadvantaged groups can be people of colour, women and people with disabilities. These groups have different starting points than more advantaged groups in the competition for social benefits. Kittay and others (Kittay et al., 2005) argue that "a politics of sameness that insists on equal access and opportunity but ignores the differences in starting points can exacerbate and perpetuate disadvantage" (p. 456). To avoid this, she advocates for a politics of difference, which should address inequalities and provide equal opportunities and access. People with disabilities are good illustrations for a politics of difference. Some people with disabilities are more prone to vulnerability and dependency, and many have unmet dependency needs. But this is not true for all people with disabilities, and they are often wrongfully construed as dependent and vulnerable. Furthermore, many disabled people are dependent in ways they do not necessarily have to be had they lived in accessible and accommodating environments, with universal design, available assistive devices and with better health and environmental policies. Good care, Kittay and colleagues (Kittay et al., 2005) argue, is providing care when it is needed, and refrain from providing care that interferes with people's freedom to exercise their capabilities and their own agency (Kittay et al., 2005). Kittay and others (Kittay et al., 2005) argue that being falsely seen to be dependent where they are not contributes to the exclusion of people with disabilities from full social participation and limits their possibility to flourish. The fact is that people with disabilities often *do* need assistance, but many argue that this is not dependence, because with appropriate accommodation and assistance, controlled by the disabled person, they can lead "independent" lives – lives in which, in all aspects apart from those requiring care, they function independently and autonomously. Adding to the view of

people with disabilities as dependent, they are also often seen as unable to provide care for people in need, when in fact many are fully capable of taking on such responsibilities. But it is a fact that many people with disabilities are dependent and need some form of care, and Kittay and colleagues (Kittay et al., 2005) argue that "by stigmatising dependency rather than dealing with the fact and variety of human dependency needs, we deny people with disabilities the respect and opportunity to flourish that is everyone's due" (Kittay et al., 2005, p. 459). The common assumption that all individuals aim to be independent can be detrimental to people with disabilities, and perhaps especially for people with severe psychosocial disabilities whose impairments often preclude them from being completely independent. Kittay and colleagues (Kittay et al., 2005) criticise politics and literature from Western industrialised nations for making assumptions about what she refers to as "the myth of the independent unembodied subject" (p. 445). They argue that one needs to accept and understand dependency and dependency needs, and meet them with fairness and kindness, to create a system for meeting such needs. They further state that "…whether our dependency needs are minimal or significant ought to be indifferent to our ability to flourish. A just society would meet those needs, however demanding they may be, within the constraints of available resources" (Kittay et al., 2005, p. 468).

In more and more societies we see that women, who traditionally provided care within the family, are in the workforce. At the same time people live longer and have more long-term care needs as they get older. The result is that family care is increasingly being replaced by care provided outside the family; by paid care givers and care institutions (Kittay et al., 2005). In many societies, especially wealthy societies, there are more people in need of care than there are care givers. The solution to this is that care workers are often imported from poorer nations, which again lead to a lack of care capacity in these countries. Adding to this, poor nations are subject to economic effects of globalisation and development, which poses a threat to traditional forms of caring. Many elderly and disabled people are dependent and need care due to lack of environmental support and adaptations. Had this been in place, these individuals would to a large extent be able to care for themselves (Kittay et al., 2005).

Similar to Tronto, Kittay and colleagues (Kittay et al., 2005) emphasise the importance of caring for the carer. This could be in the form of, for instance, material resources, emotional support, assistance and monetary compensation. The question is, who should care for the carer? Care is not always a reciprocal relationship where the care giver and care receiver can care for one another. On the contrary, those who are cared for are often not able to reciprocate the care, and so a third party must care for the care giver. It is also crucial to ensure that the care provided by the care giver is not given at the expense of other important care relationships in his/her life. For instance, the migration of care workers from poor countries to wealthier nations

often has major negative impacts on the health services, communities and families they leave behind.

Engster

Engster (2005) has reformulated caring so that it can form the basis of a moral and political theory, arguing that care is gender neutral, as it is first and foremost about meeting basic human needs (Sander-Staudt, 2011). He argues that Tronto and Fisher ground the care concept in an objective, material and moral foundation, and that a more suitable definition would include a specification of what caring attends to in maintaining and repairing human life and society. Caring, Engster (2005) says, is not just about achieving a certain aim, but also about doing so in an appropriate manner. Some scholars have argued for a distinction between productive labour and care, in that productive labour is something we do to secure resources for ourselves and others, while care is what happens before and after the productive labour (Engster, 2005). Engster (2005), however, defines care as a form of reproductive labour that fulfils three aims crucial for the survival, development and social reproduction of an individual (Engster, 2005, p. 51). These three aims are: 1) Satisfying basic biological needs necessary for functioning and survival, such as food, sanitation, clothing, shelter, rest, medical care and protection from harm; 2) Helping others develop and sustain basic capabilities, such as sensation, emotion, movement, speech, reason, imagination, affiliation, literacy and numeracy; and 3) Helping individuals avoid or relieve suffering and pain, so they can carry on with their lives as well as possible. The overall goal of caring is described by Engster (2005) as "(helping) individuals achieve at least a basic level of well being, meaning, at a minimum, survival and as much basic functioning as they are able to achieve" (Engster, 2005, p. 53). What constitutes basic wellbeing varies across and within different societies, according to age, health status/abilities and more. Some commonalities, however, can be found, such as wanting lives free from malnutrition, illness, exhaustion, pain and physical danger. Engster (2005) argues that self-care is an important component of care, and that it is crucial that carers care for themselves, as someone who does not care for him/herself is unable to care well for others. Some human characteristics are crucial in providing care for others, and while care theorists have described these differently, Engster (2005) describes three commonalities that can be found in the care literature. These are: 1) Attentiveness and empathy; noticing the need for care in others and responding to this need; 2) Responsiveness; going into dialogue with the person in need of care to determine the nature of his/her needs and preferences for care; 3) Respect; the idea that all human beings are worthy of attention and responsiveness, that they understand and can express their own needs, and that people are not less worthy because they are in need of care. Respect is shown by caring for people without degrading them and acknowledging their abilities.

In summary, Engster (2005) defines care as ". . .everything we do directly to help others to meet their basic needs, develop or sustain their basic capabilities, and alleviate or avoid pain or suffering, in an attentive, responsive and respectful manner" (p. 55).

Engster (2005) criticises Tronto's approach to care as "practices we do to maintain, continue and repair our world" for being too broad. He argues that within this definition practices like house building and plumbing can be seen as care, but in most cases they are not. He further states that it is the overall aim, and not the practice itself, which constitutes the caring. House building, for instance, can be a caring activity if people come together voluntarily to build houses for the homeless, but not if the activity is performed with the aim of making money. He mentions parenting, teaching, tending to the sick and elderly, counselling and mentoring as common care activities.

Despite the fact that caring practices are seen as highly contextual and culturally dependant, cross-cultural studies have found few differences. Care needs, and the fact that these are responded to, are to a large extent universal. Across all cultures, children, elderly and sick people have care needs and are cared for in one way or another. Strategies to address these needs, however, differ somewhat across cultures.

Many care theorists argue that an activity should be described as care only if the person who is cared for is unable to do the activity for him/herself. When a person is able to do the activity for him/herself, but another person does it instead, it should be considered a personal service rather than care. Engster (2005), however, argues that some personal services should be considered care, such as everyday caring among adults. He does not distinguish between personal service and necessary care, but argues that the obligation to care is not present when the care receiver can meet his/her own needs. Engster (2005) identifies three ways to care for others: 1) Personally caring for another; 2) Caring for the carer by ensuring that the carer has the resources and support needed to provide good care; and 3) Collective caring; supporting or instituting programmes that directly help people meet their own needs.

The theory of moral obligation is central to ethics of care, in its attempt to understand why people should care for others, and who we should care for. While caring has traditionally been seen as a voluntary practice, Engster (2005) argues that humans have a duty and responsibility to care for others. Several factors can be seen as motivational for care, such as affection, love, empathy and the well-being of another being tied up to own well-being. We have a special obligation to care for family and friends, because we are in a position where we can easily help or hurt these people, and therefore we are more responsible for their well-being. The question is, if there is no motivation to care for another, can there still be a duty to care? Engster (2005) argues that "we may all be said to have obligations to care for others not so much because

others are vulnerable to us, but rather because we are dependent (and have been or will be) upon others" (p. 59). All human beings need care at one point or another, during childhood, illness, disability or old age. We even need some form of care during times of wealth and vigour. As a result, there is an inevitable relationship between care and dependency, which has also been referred to as the web of dependency. When we provide care or are cared for we are part of this web. Care receivers are dependent not just upon their primary care givers, but also upon those that support and accommodate the care givers so they can provide care (Engster, 2005). The web of dependency is seen by some theorists as a major reason for people to care for one another, purely out of self-interest. As Engster (2005) explains:

> Ensuring good care for individuals in our immediate social environment will increase the likelihood that we will be surrounded by more capable, sociable and satisfied, and fewer incapable, maladjusted, and desperate, individuals. This in turn will enable us to live fuller and safer lives, and increase the probability that we will receive good care when we need it. (p. 61)

Some people, however, will try to reap the care benefits with little or no contribution to it themselves. Furthermore, if our obligation to care is purely out of self-interest we would care only for the people closest to us, and neglect others, which Engster (2005) argues that some people in fact do. Many care theorists reject this approach to our duty to care, arguing that our feelings of duty are intuitive and moral. Some argue for a principle of fairness, stating that all individuals are obligated to contribute to the maintenance of any cooperative scheme that mutually benefits them. Engster (2005) rejects this view based on two main arguments; it limits our caring duties to people that are in our web of caring relations, and to those who can contribute to this web themselves, ending up excluding many people who are in need of care, but who are not able to provide care for others in return.

Care theorists commonly see our obligation to care as linked to our common dependency, rather than individual choice. Given our need for various types of care throughout our lives, caring for others in need is a necessary obligation if we want to have the right to be cared for when we need it ourselves. Engster (2005) states that,

> . . .we should care for others in need when we are able to do so because we have implicitly demanded and continue to demand care from others for our own survival and development and the reproduction of society; and because denying others the care they need deprives them of the support necessary to survive and achieve the basic well being that we all implicitly recognise as good. (Engster, 2005, p. 65)

2.3.2 Health care

Health care is often thought of as synonymous with scientific medicine. In this dissertation, however, health care is approached from a broader perspective, to include traditional, Western/scientific and more informal forms of health care. These will be described below.

Pluralistic health care systems

> Health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right… (WHO, "Declaration of Alma Ata", 1978a)

This dissertation concerns itself with care for people living with psychosocial disabilities or reduced mental well-being, which is an essential part of the overall concept of health (WHO, "Declaration of Alma Ata", 1978a; WHO, 1948). Much of the care for these individuals takes place within various health care systems. Most urbanized societies, both Western and non-Western, have health care pluralism. In these societies different treatment and care approaches co-exist, based on different premises, originating from different cultures. The ill person, however, is primarily concerned with the efficacy and acceptability of an approach, and less about its origin. A society's health care system is interwoven with and based on similar assumptions, views and values as its social, religious, political and economic organisation. Most societies have one dominant form of health care, usually upheld by law. In Western countries this dominant form of health care is scientific medicine (Helman, 2007). One of the earliest accounts of a pluralistic health system was made by Janzen in his iconic book "The quest for therapy: Medical pluralism in Lower Zaire" (Janzen, 1978). His work paved the way for a contextual understanding of a pluralistic medical system, combining African and Western approaches to illness and healing. His study provided insight into the total health care scene in one region of Lower Zaire, and has since offered guidance for studies on health care systems and for improvement of health care. Janzen (1978) defines health care systems (he uses the term medical systems) in the following way:

> Medical systems, pluralistic and homogenous alike, have been defined here as concepts and values related to techniques practiced by individuals in corresponding role relationships. (Janzen, 1978, p. 223)

He identifies four therapeutic systems in Lower Zaire, which will be briefly described below. These systems all have their histories, and they are all imbedded in the social consciousness, rules and behaviour of the people in one way or another. This means that medical ideas, values, techniques and roles are rooted in the local culture of each therapeutic system's origin (Janzen, 1978). The systems are:

1) The art of the Nganga: This is a form of spiritual healing in which the Nganga is the healer, an agent of God, who together with God treats the whole person. The Nganga deals with the external person and God deals with the inner person. Healing happens in the form of praying or chanting. There are two types of Nganga healers; the herbalists and the magician. The herbalists treat illnesses without supernatural causes, while the magicians treat illnesses with both physical and behavioural manifestations, such as anger. Causes of illness in this form of healing are understood as "of God" in the case of direct and natural illness, or it may be "of someone in the evil world", particularly in relation to "anger illnesses". That something is "of God" does not imply a particular divine intervention, but rather that it is beyond human intention, part of the natural order of things.
2) Kinship therapy**:** At the heart of this therapy is a clan meeting, which usually only takes place when the illness is considered to be particularly serious. There are diagnostic and therapeutic clan meetings. But before the clan meeting happens, kin therapy managers will have assisted with care seeking from other therapeutic systems. The clan meetings only deal with illnesses caused by witchcraft or magic. Therapeutic approaches in kinship therapy are conflict resolution, blessings, gift exchanges, sacrifices or food distributions. The clan may also decide to consult another therapy form. In the past, identification and punishment of witches who had caused the illness was common, but this rarely happens today, as it has been banned by law.
3) Purification and initiation: This treatment is mostly handled by prophets. Purification is about cleaning the body of the “dirt” or pollution that is the illness. This happens through ritual techniques, such as purificatory baths, anointments, isolation, laying on of hands, prayers, mediation or songs. While these prophets believe that social relationships play a role in creating disease, they do not investigate or treat social relationships as causes of illness. They prefer to stay away from this investigation, regarding it to be dangerous. These prophets commonly do not deal with origin of illness; they just heal what they see.
4) Western medicine: These are medical techniques and practitioners associated with scientific medicine, such as immunization, paediatric-, obstetric- gynaecologic- and surgical care, nursing, and physiotherapy. Western medicine in an African context is usually provided by mission societies, governments or health organisations. In Lower Zaire this medicine is seen as a system equipped to deal with physical and chronic disease (natural diseases "of God"), but not to deal with the social and personal context of these diseases, or to offer the patient a comprehensive explanatory model for disease. Illnesses such as anxiety, anger, social conflict, witchcraft and magic are seen as outside the capability of Western medicine. Western medicine largely ignores and devalues aetiologies for illness common in the local population, and as a result creates a common assumption among the locals that Western medicine is incompetent. In most African contexts, Western

medicine has official government support, is regulated by law, and practitioners, both of European and African origin, enjoy a great deal of power in African society.

Janzen (1978) expresses several concerns about Western medicine's entry into the life and consciousness of the people of Lower Zaire. He found that modern Western medicine, relatively "new" to Zairian society, was active, accepted and used alongside traditional forms of medicine, but not at the expense of the traditional medicine with its long history and deep roots in society. He argues that Western medicine is based on wrongful assumptions of authoritative physicians and compliant patients. The patient must convince the physician of his/her symptoms of illness, and the physician has to convince the patient of the appropriateness of the prescribed treatment. Confidentiality and privacy in the patient-physician relationship is crucial in Western medicine. In reality the patient-provider relationship is charged with misunderstandings, disbelief and disagreement, and as a result there is a lot of non-compliance. Better patient-provider communication could assist with this problem, as much of the problem is rooted in the patient's lack of knowledge and understanding of the medicine and treatment prescribed by the physician. Furthermore, the impersonal and bureaucratic, although loyal, nature of Western medicine does not resonate well with Zairian notions and expectations of therapeutic interventions.

While Zairians are also extremely loyal to prophets or cult leaders, this relationship is highly personal. Adding to this, in traditional medicine privacy and confidentiality between healer and patient is uncommon, and therapeutic interventions are often carried out in public. Traditional healers, lacking support from the state and the solid ideology of Western science, do not assert their expertise in the authoritative manner Western practitioners do. Rather, alternative authoritative techniques are used, such as mystical authority, or involving a third party, which Janzen (1978) refers to as a therapy management group (family/friends/community), to put pressure on the patient to comply with the treatment. The involvement of a therapy management group requires social and cognitive consensus on the cause of the illness and the best therapeutic option for that particular illness. This cannot be imposed upon them. Consensus combined with correct diagnosis and treatment, Janzen (1978) argues, is essential for effective delivery of health care in a pluralistic medical framework. Consensus must involve the medical practitioner and the patient, but usually also involves the lay therapy managing group described above. The importance of consensus is something that is often ignored by Western physicians, who often take their authoritative position for granted. Janzen's work from Lower Zaire emphasized the importance of consensus in social groups in determining treatment outcome; in fact, social groups are as influential as individual beliefs. The therapy management group is described as crucial in understanding pluralistic medical systems. While this group is interested in pushing the patient to continue treatment in Western medicine until

he or she has recovered, their conviction that less tangible and more mystical causes are at the root of many illnesses often leads them to seek treatment from traditional forms of medicine alongside Western medicine. These traditional forms of medicine, they believe, are more suited to deal with problems of, for instance, anger, conflicts or life crises.

Janzen (1978) argues for a shift in emphasis from a narrow view of medical techniques to a broader view to include these techniques, in addition to popular expectations and views of medical practitioners and medicine. In his study in Lower Zaire this approach provided him with a better insight and understanding of illness and health care. He writes that a critical question to ask for medical practitioners, medical institution builders and policy makers is the following:

> How can the practical responses to physical disease in Western medicine be combined with the deeper social, emotional, and mystical responses of African medicine, without exacerbating the afflictions of individual sufferers? (Janzen, 1978, pp. 226-227)

He offers some suggestions for solutions to this question. First, he suggests synchronising services, making sure that practitioners refer patients to other appropriate practitioners in the total health care system if they cannot complete treatment themselves. In his study Janzen (1978) found that all the African practitioners of traditional medicine referred to all the other medical institutions, also Western medicine. African practitioners of Western medicine sometimes referred to practitioners of traditional medicine, and they allowed members of the therapy managing group to be present during diagnosis and treatment. European practitioners of Western medicine, on the other hand, only referred patients within the Western medical system, and not outside. Janzen (1978) argues that a "well-informed referral network is a key feature of total therapy in a pluralistic medical system such as exists in Lower Zaire" (p. 227).

Another suggestion is synchronised plural therapy, integrating traditional forms of medicine with Western medicine and synchronising these treatment efforts. He argues for the potential usefulness of combining Western medicine with traditional therapies, such as using therapy management groups to ensure the patient complies with treatment, or for them to carry out certain forms of Western medicine treatment, such as carrying out support groups for psychiatric patients.

Solutions like the ones above are, however, not without challenges, and especially in a context where health providers from different therapeutic systems have competing and conflicting views. As Janzen (1978) points out:

> It is in the logistics of multiple therapy-courses that difficulties arise, . . .where life-saving medication is overlooked while social conflicts are resolved. (p. 227)

The medical system of Lower Zaire is rapidly changing, with more and more Western practitioners being locals, and the traditional medicine, while still active and present, being increasingly replaced by friends, co-workers, religious communities and neighbours of the sufferers. Western medicine is expanding, but traditional medicine remains strong. As uttered by a traditional practitioner (freely translated by Janzen): "You and your medicine are great, but they are temporal; ours is the eternal medicine of the ancestors" (p. 229).

Another influential approach to a pluralistic health care system is that brought forward by Kleinman (1980) in his famous book "Patients and Healers in the Context of Culture" from 1980. This approach has been further developed and described by Helman (2007) in his book "Culture, Health and Illness", with the fifth, and latest, edition published in 2007. Kleinman (1980) describes health care as a local cultural system, integrating the health related components of society. Patients and healers are key components of this system. The health care system, he argues, is composed of three overlapping sectors (see Figure 2), each with their unique way of perceiving, interpreting, labelling and treating illness. Each sector has different approaches to who the carer and the cared-for are, what their roles and responsibilities are, and how they should interact with one another. The sectors are: 1) the popular sector, 2) the professional sector, and 3) the folk sector (Kleinman, 1980). These are described below.

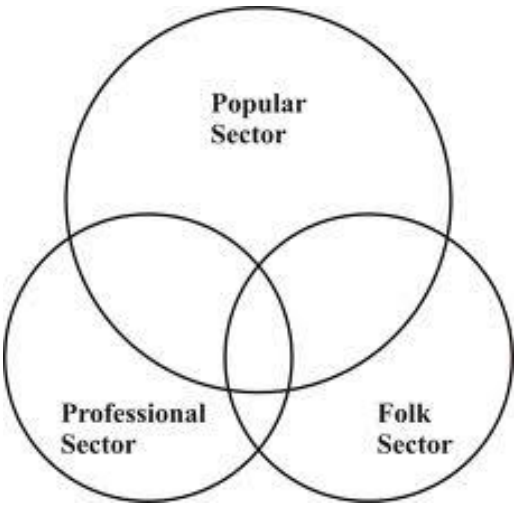


Figure 2. Kleinman's (1980) three sectors of health

1) The popular sector is the largest, but least studied of the three sectors (Kleinman, 1980), where an estimated 80-90 % of the care happens in both Western and non-Western societies (Helman, 2007). Care that takes place in the other two sectors is usually anchored in beliefs and practices from the popular sector. This sector refers to the individual, family, social networks, community beliefs and activities (Kleinman, 1980), and is often referred to as "the real site of primary health care" (Helman, 2007, p. 82). It is a non-professional and non-specialist arena, consisting of lay people and anchored in popular culture. In this sector care happens without consultation or payment of carers from the professional or folk sector (Kleinman, 1980). Kleinman (1980) argues that this is the sector where illness is usually discovered and care decisions are made, initiated and evaluated, and also the sector people return to during and after they have received treatment from any of the other sectors. As such, Kleinman (1980) argues that "the popular sector functions as the chief source and most

immediate determinant of care" (p. 51). The popular sector is more concerned with health and health maintenance than it is with sickness and treatment (Kleinman, 1980). Strategies for health maintenance and treatment of illness are anchored in lay beliefs about the structure and function of the body, beliefs about what good and bad health constitutes, as well as the origin and nature of health and illness. Such beliefs are highly contextual and cultural. Health maintenance is described as culturally specific guidelines about the best way to prevent illness in oneself and others, such as healthy eating, drinking, sleeping, dressing, working, praying and other aspects of life. In some societies health is maintained through the use of charms, amulets and medalions believed to ward off illness caused by bad luck and attract good luck and good health. Treatment of illness can take the form of patent medicines, traditional folk remedies, "old wives tales", or changes in diet or behaviour (Helman, 2007). In most societies and cultures self-care is the first treatment intervention for illnesses, and self-care happens in the popular sector (Kleinman, 1980). Additional care in this sector happens amongst people who are familiar with each other in one way or another, first and foremost family members (Helman, 2007), but it can also be close friends, neighbours or members of work or religious organisations (Helman, 2007; Kleinman, 1980). In this context women are usually the main providers of health care (Helman, 2007). In the popular sector the individual with the illness is first and foremost a sick family member, a friend, a neighbour and so on, and as such, the carer and the cared-for usually share similar beliefs and assumptions about health and health care, reducing the risk of miscommunication and disagreement between the two (Kleinman, 1980). The popular sector comprises informal and unpaid care, without fixed rules or roles. The person in need of care one day, may be the carer the next. Care happens in the social network of the cared-for (Helman, 2007). Helman (2007) argues that, within the popular sector, there are certain individuals people tend to turn to for health advice, individuals who are considered particularly knowledgeable and resourceful about health matters, usually because they have experience about these things, rather than having an education, a particular social status or special occult powers. Self-help groups are common arenas for sharing experience and advice on particular health related topics. These groups make up an important and substantial part of the popular sector in Western countries, and bring many benefits to its members, such as sharing advice and being a social and support arena for isolated individuals (Helman, 2007). The treatment and care taking place in the popular sector can both facilitate and impede health care. For instance, there are many examples of the wonderful care provided in a family context, but there are also examples of families containing or hiding the sick individual and the problems generated by illness in the family (Helman, 2007).

2) The professional sector comprises organised healing professions, subject to a great deal of professional control, legal sanctioning and systematic research proving its efficacy (Helman, 2007; Kleinman, 1980). It is usually synonymous with modern Western scientific medicine, but in some societies there are indigenous medical systems that are organised and professionalised similar to modern medicine, for instance Chinese medicine and Ayurvedic medicine (Kleinman, 1980). Most societies have their own ethno-medicine, arising from and influenced by that society's social structure, culture, world-view and belief system. Scientific medicine can be seen as the ethno-medicine of the Western world, but over the past century it has spread to much of the globe (Helman, 2007). As a result, it has become the dominant health care system in most societies, and research on health care has traditionally seen modern medicine as the entire and total system of health care, without recognising the rest of the health care system (Kleinman, 1980). Kleinman (1980) argues that health providers from the professional sector also tend to pay attention only to the medicine that they practice, ignoring other aspects of health care. He states that; "the health care system is a great deal wider than the boundaries of the modern medical profession, even in technologically advanced societies" (p. 58). As a result, practitioners in this sector are often dismissive of and pay little attention to the perceptions, interpretations, labelling and care that take place in the popular and folk sector (Kleinman, 1980). In reality the professional sector makes up only a small proportion of the total health care system in most parts of the world. The severe lack of medical practitioners in this sector, particularly in low-income countries, further strengthens the position of the folk sector in these societies (Helman, 2007). Health providers in the professional sector include various types of physicians, nurses, midwives and physiotherapists. In most societies these are the only healers whose positions are upheld by law, leaving them with a great deal of power and responsibility (Helman, 2007). In the professional sector the person in need of care is seen as a patient or a client, rather than an individual with unique needs and perspectives (Kleinman, 1980).
3) The folk sector, referred to as non-professional, non-bureaucratic and non-specialist, consists of healers and indigenous practices of various kinds (Kleinman, 1980). These healers practice forms of healing that are sacred or secular, and are not part of the official medical system. Most folk healers have little or no formal training. Some get their skills through training with an experienced healer, or through inheritance, others are born with healing powers, or discover "the gift" of healing later in life (Helman, 2007). Folk healers are a heterogeneous group, ranging from midwives (traditional birth attendants), tooth extractors, herbalists, spiritual healers, clairvoyants to shamans. There is great variation between and within different types of practices in the folk sector,

but in some countries or regions they are organised into associations, and as such subject to some ground rules, codes of conduct and sharing of information (Helman, 2007). Despite variations, healers in this sector commonly use some of the same healing techniques. One example is among the Zulus in South Africa, where sacred divination is carried out by female *izangoma* (plural of *isangoma*), while treatment with herbal medicine is carried out by male *iinyanga*, but both practices rely on information about the patient's social background and details of his/her illness for diagnosis (Helman, 2007). Healers in the folk sector often live and work in the same physical and cultural context, and as such share the same cultural values, beliefs and world views as their patients, including beliefs about origin, cause and treatment of disease. Folk healers are particularly common in contexts where illness and misfortune is attributed to social and supernatural causes, such as witchcraft, sorcery, gods, spirits, ancestral ghosts and fate. These healers often take on a holistic approach to healing, dealing with all aspects of the patient's life, including relationships, the natural environment in which they live, supernatural forces and physical and emotional symptoms of illness. Adding to this the family of the patient is often involved in the process of diagnosis and treatment. This holistic approach usually reflects the approach to health and illness in the overall population, where health and ill health is seen as a balance or imbalance between people and their natural, social and supernatural environment (Helman, 2007). Helman (2007) argues that there are several advantages of folk healing over scientific medicine, especially in dealing with psychological problems. First, the inclusion of the family in the diagnostic and healing process, and also the holistic approach, taking all aspects of a person's life into consideration. Furthermore, the context where healing takes place is usually a familiar context to the patient; in the community where they live, and with a healer that they are familiar with. Finally, folk healers deal with all kinds of health problems; physical, psychological, social and spiritual, where these in scientific medicine would be dealt with separately by different types of health providers (Helman, 2007). On the other hand, folk healing has disadvantages and dangers. Healers may ignore, misdiagnose or mistreat signs of physical and mental illness, thereby delaying or hampering necessary treatment, causing physical or psychological damage to their patients. They may use inappropriate or inadequate equipment and medication, which can lead to the spread of infections or dangerous side-effects of the treatment. Stories have also been told about folk healers that exploit their patients financially, emotionally or sexually (Helman, 2007).

The folk sector is closely related to the popular sector, with some aspects of it related to the professional sector (Kleinman, 1980). The relationship between the folk sector and the professional sector is often characterised by mutual distrust and suspicion.

> Many medical doctors believe folk healing does more harm than good; posing a threat to the health of their patients. But increasingly health authorities and the World Health Organisation are recognising the benefits and the extent of folk healing in many parts of the world, and as such are trying to turn the folk sector into an ally of the professional sector, rather than an enemy. While a successful collaboration between the folk sector and professional sector is challenging, there are examples of its success, for instance in relation to AIDS prevention, TBAs, family planning and treatment of mental illness (Helman, 2007). In some societies where the professional sector is lacking, the folk sector and the popular sector comprises the entire health care system. From the folk sector, religious and sacred forms of healing have received most of the research attention, especially by anthropologists, while other aspects of the folk sector, such as herbalism, traditional surgical and manipulative treatments, have received less attention. There are hardly any systematic follow-up studies of patients treated in the folk sector, and hence, the efficacy of the treatment and care that takes place in the folk sector can be questioned (Kleinman, 1980).

The three sectors described above interact because patients pass between them, with the popular sector commonly being the link between the professional and folk sector. While the popular sector closely interacts with the other two sectors, there is usually little or no interaction between the professional and folk sector (Kleinman, 1980). The ill individual, however, moves freely between the popular sector and the other two sectors, often seeking care and treatment from all three sectors concurrently (Helman, 2007). In the literature, the popular sector has received much less attention than the other two sectors, which, Kleinman (1980) argues, is a paradox, given that this is by far the largest, most active and widely used of the three sectors. He further argues that too much attention has been given to the exotic and dramatic, but less important, folk sector (Kleinman, 1980).

Kleinman (2008, 2009, 2012) sees caregiving as part of what it is to be human; a moral experience that is part of the collective, social, political and individual values and emotions that make up everyday life. He refers to caregiving as an art, one that is often overlooked in a professional sector context where the doctor-patient interactions often last only a few minutes, hardly enough for basic physical examination, leaving little or no time for questions and communication. He argues that "(the medical interaction is) not a place where the art of caregiving is likely to flourish" (Kleinman, 2008, p. 22), that modern medicine should comprise both the art of care giving and the science of medicine, and that these are interlinked. Diagnosis, treatment and prognosis are as much about the patients' history, their interpretations and their social context, as they are about pathophysiology and pharmacology. But while the science of medicine is learned and maintained through comprehensive training

and scrutiny, Kleinman (2008) questions where the skills and knowledge required for caregiving come from. Indeed, he argues that the process of learning scientific medicine disables the physician as a care giver (Kleinman, 2008).

While Kleinman (2008; Kleinman & Benson, 2006b) emphasises the importance of providing doctors with insight into local and cultural interpretations of suffering and caregiving, he argues that there is no single discipline or strategy alone that can do this (Kleinman, 2008). One must be careful not to confuse cultural competency with a technical skill in which health professionals can be trained in order to develop expertise. Culture is often understood as synonymous with ethnicity, nationality and language, and assumptions are made about people based on these attributes. This thinking can lead to stereotyping which can cause more harm than good (Kleinman & Benson, 2006b). Kleinman and Benson (2006b) argue that culture is not homogenous or static, and it is inseparable from economic, political, religious, psychological and biological conditions. Culture is often different within the same ethnic or social group because of differences in, for instance, age, gender, class, religion, political association, and even personality. Kleinman and Benson (2006b) describe culture as "a process through which ordinary activities and conditions take on an emotional tone and a moral meaning for participants" (Kleinman & Benson, 2006b, p. e294). To gain cultural competency, doctors need to learn the skills of acknowledging and affirming patients' many ways of responding to suffering, and how to communicate with and support patients on what really matters to them (Kleinman, 2008). Such training, combining practice and theory, would require an innovative and multidisciplinary approach, combining, amongst others, medical, historical, cultural, artistic, ethical and religious perspectives (Kleinman, 2008). Kleinman (2008) further argues that, in addition to medical training, the doctor's view of the world, based on personal and cultural resources, influences his/her practices of medicine and care giving (Kleinman, 2008).

While scientific medicine is practised in the professional sector, usually by doctors, care giving is much broader, including skilled nurses, social workers, rehabilitation professionals and homecare (Kleinman, 2008, 2012). Kleinman (2008) argues that the majority of caregiving is provided in the private sphere (popular sector), by families and intimate friends of the person in need of care. Caregiving in the private sphere takes the form of assistance to perform activities of daily living, financial aid, legal and religious advice, emotional support, meaning-making and remaking, and moral solidarity. Despite the extent of these caregiving activities, we know very little about them (Kleinman, 2008).

Based on his own experience of being a care giver for his wife suffering from Alzheimer's disease, Kleinman (2009) stresses the importance of also caring for the carer through practical

and emotional support. He describes caregiving as a defining moral practice, but one that is tiring, emotionally draining, time and resource consuming, and charged with feelings of loss, anger and frustration. At the heart of caregiving, however, are feelings of love, solidarity and responsibility (Kleinman, 2009, 2013a). Caregiving is difficult, and far more complex than often presumed by medical professions. The skills of caring are usually learned by doing in the interaction between care giver and care receiver (Kleinman, 2009, 2013a).

Accessibility to scientific health care

Accessibility to modern, scientific health care is conceptualised according to the General Comment (no.14) of the United Nations Committee on Economic, Social and Cultural Rights (UN, 2000). The General Comment serves as a useful tool to better understand the facilitators and barriers to accessing biomedical health care. The indicators of good services, as outlined in the comment, encompass four intersecting elements.

1. Accessibility refers to the need for health facilities, goods and services to be accessible to everyone without discrimination, and within the jurisdiction of the State. This first element of accessibility has been further broken down into the related dimensions of non-discrimination, physical accessibility, economic accessibility (affordability) and information accessibility.
2. Availability concerns the quantity of service available; functioning public health and health-care facilities, goods and services, as well as programmes, have to be available to the general public in sufficient quantity.
3. Acceptability stresses that all health facilities, goods and services must be respectful of medical ethics, be culturally appropriate, sensitive to gender and life-cycle requirements, as well as designed to respect confidentiality and improve the health status of those concerned.
4. Quality is the element which requires that health facilities, goods and services must be scientifically and medically appropriate to provide services of good quality (UN, 2000).

A WHO report from 2002 (WHO, 2002) states that long-term care for people with chronic illnesses and disabilities presents a challenge around the world, particularly in many developing countries where care needs are estimated to increase by 400% over the next decades. The report also states that current care systems in these countries are not sufficient to meet this increased need, and outlines some of the issues that need to be considered in developing systems of care for the future. Historically and currently care systems around the world are dependent on unpaid family members, but there is a need for states to take on a larger responsibility and make sure that the necessary care resources are available and distributed equitably. States must make sure that care is organised according to existing care

needs, available resources and principles of justice (WHO, 2002). Societies have an ethical obligation to provide care; to make sure that those with resources can fully enjoy their benefits, while those less fortunate are provided with necessary support and security. Many societies experience bias in care provision related to individual attributes such as gender, age and disability, as well as geographical attributes, such as rural location. It is crucial for such attributes to be recognised in planning and implementation of care activities (WHO, 2002).

It is also important to recognise gender differences and value placed on women in care activities. In most societies women make up the majority of the care givers, and care work remains undervalued (WHO, 2002). While many states are dependent on family care, it is important not to build care systems on the assumption that the family is the first-line provider. While this may be true for some, it is not for all, and this assumption should be questioned. Furthermore, strengths and weaknesses of family care should be assessed, and societal structures should be in place to intervene and support where needed. This could be through training, access to information, respite care or opportunities to talk about worries and concerns. Support from outside the family unit should aim to enhance, and not disrupt, the intimate relationship between the carer and the cared-for.

There is often poor communication between acute care and long-term care, as well as between families and health care professionals. Communication channels can be difficult to build, however, as family concepts of intimacy, privacy, confidentiality, and decision-making often clash with the values of health care professionals (WHO, 2002). In addition to family care, an individual, especially in communal African cultures, is often a member of several communities and organisations that provide some form of care, such as clans, villages, women's groups, religious groups and professional associations (WHO, 2002). Individuals are also responsible for caring for themselves, but the degree to which this should be expected is questioned by WHO (2002), stating that "it is legitimate to ask how much individuals can do for themselves in societies where they are challenged even to remain adequately nourished" (p. x). There are many ways to define the roles and expectations of a care giver, and many different relationships between care giver and care recipient. The ethical obligations of care givers, WHO (2002) argues, have not yet been extensively explored, but some guidelines are provided: First, it is important for both the care receiver AND care giver's voices to be heard. Second, care providers must have the required knowledge, training and skills, and they should be equitably compensated, have attractive working conditions and access to training and advancement within the system.

2.3.3 Occupation as care

> Everyone has the right to be occupationally active in health-giving and developmentally enriching pursuits. (Watson, 2004a, p. 62)

It has been argued that participation in occupational activities is a crucial part of care and healing, and is key to transformation and growth both at individual and at community/societal level (Higson-Smith, Richter, & Altman, 2004; Pereira & Whiteford, 2013; Reed, Hocking, & Smythe, 2010; Vessby & Kjellberg, 2010; Watson, 2004b). Transformation happens through the opportunity to express choice, make decisions, and experience occupational achievement and enrichment (Watson, 2004a). The field of occupational science has a long and comprehensive history, the totality of which cannot be covered in this dissertation. Of particular relevance to this dissertation is the meaning and importance of occupational participation in people's lives, and the link between occupation and care.

From an occupational science perspective, occupation is understood as the things people do in their everyday lives (Sundkvist & Zingmark, 2003), described as "a recognisable everyday life endeavour, in which a person engages or participates" (Pereira & Whiteford, 2013, p. 113). This understanding is much broader than occupation seen only as employment with the ultimate goal of making money (Pereira & Whiteford, 2013). The concept of participation is central to both occupational therapy and health care, through the Model of Human Occupation (MOHO) and though the ICF framework (Vessby & Kjellberg, 2010). Participation, as conceptualised in ICF, is described as "involvement in a life situation" (WHO, 2001b, p. 14). MOHO defines occupational participation as "engagement in work, play or activities of daily living that are part of one's sociocultural context and that are desired and/or necessary to one's wellbeing. Engagement involves not only performance but also subjective experience" (Kielhofner, 2007, pp. 101-102). While participation is closely connected to involvement in the environment, including interaction, involvement and engagement with other people, with the physical environment and with society, it is also connected to engagement in activities people value and find meaningful, which again is closely linked to quality of life (Vessby & Kjellberg, 2010). Occupation is commonly seen as a phenomenon which requires cultural understanding, with apparently similar activities having different meanings in different contexts. The meaning of occupation is socio-culturally derived (Reed, Smythe, & Hocking, 2013; Whiteford & Wilcock, 2000). Occupation changes throughout our lives, influenced by many things, such as personal capacity, culture, norms, values, illness and adversity. Another important influence is where people live, and the variety and range of choices available in that context (Watson, 2004b). The physical and social environment can act both as barriers and facilitators for participation in occupation (Vessby & Kjellberg, 2010). Sometimes people are excluded from their desired

occupations, either through personal choice or through lack of opportunity (Watson, 2004b). Environmental factors can enable or restrain people's participation in occupation. In the past, the environment was seen as static, and people were either adapted to the environment or not. Through the development of ICF and the social model of disability a broader understanding of participation has emerged, where individuals are seen as active participants in their environments, with a reciprocal relationship between environment and person/community/population (Watson, 2004a).

Occupational science commonly differentiates between occupational deprivation, occupational disruption and occupational dysfunction (Whiteford, 2000). Occupational deprivation is described as "a state of preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the immediate control of the individual" (Whiteford, 2000, p. 201). Thus, deprivation happens due to forces which cannot be controlled by the individual, as opposed to forces and limitations within individual control. Occupational disruption is a temporary state that, given supportive conditions, will resolve itself. A person can be disrupted from his/her normal occupational activities due to major life events, environmental changes, temporary illness or injury (Whiteford, 2000). Occupational dysfunction is encapsulated in a complex of factors seen "either as a by-product of non-resolved occupational disruption, as a result of specific occupational performance deficits, or as arising from a prolonged state of occupational deprivation" (Whiteford, 2000, p. 201).

Employment is, for many, their major occupational activity. Employment is important for financial gain, but is also an important part of people's personal identity, linked to self-worth, connectedness to others, possibilities for growth and development, and a sense of meaning. Thus, unemployment does not only have economic consequences, but also social and health consequences (Higson-Smith et al., 2004).

A study of the meanings attached to occupation found that these are shaped by an interplay of what calls people to action, of being with others and of the possibilities connected to occupation (Reed et al., 2010). The authors argue that "in our existence, it is the care and concern that we have for others or the things in the world that calls us to action" (Reed et al., 2010, p. 144). People are called to occupy themselves with things that matter the most to them, and this is reflected in the occupations they choose or choose not to engage in. Therefore, occupation is at the heart of who we are. Furthermore, engaging in occupations together with others gives people a sense of connection, which again gives meaning to the occupation. Being with others is a significant part of meaning, and occupation is a major reason for people to come together (Reed et al., 2010; Whiteford, 2000). Finally, through occupation people become aware of opportunities opening up or closing down for them, and it is a way to show

others what they are capable of (Reed et al., 2010). Occupational achievement is often linked to independence, which, some argue, is a Western cultural construct, and not necessarily desirable in all cultural value systems. On the contrary, independence is sometimes seen as a social failure in cultures where interdependence is the norm (Whiteford & Wilcock, 2000).

From the definition of occupation and meanings of occupation described above, occupation is central to life, to our humanity, and with major transformative potential (Pereira & Whiteford, 2013; Whiteford, 2000). Through occupation people develop their abilities and potential (Watson, 2004b), and failing to bring out this potential can lead to inadequate personal fulfilment and dependency (Watson, 2004a). It has also been argued that occupation can contribute to the achievement and maintenance of optimal physical and mental health, by living in a way, and engaging in meaningful occupational activities, that are conducive to good health (Higson-Smith et al., 2004; Watson, 2004b; Watson & Swartz, 2004; Whiteford, 2000).

2.3.4 Global mental health

In the seventies the British Journal of Psychiatry published a series of articles on mental health challenges and priorities in developing countries, and many of the major issues highlighted in this series are still true today, such as the high burden of mental disorders in low-income countries, lack of human resources, consequences of stigma and the need for task-shifting (Carstairs, 1973; Cohen et al., 2014; Giel & Harding, 1976). The term global mental health, however, was only introduced around the turn of the century, and became a commonly used and accepted term after it was used in the 2007 Lancet Series on Global Mental Health (Cohen et al., 2014; Horton, 2007; Mills, 2014). Since then global mental health has become an emerging field within global health, striving for equity, aiming to "improve treatments, increase access to services, and reduce human rights abuses of people experiencing mental disorders" (Cohen et al., 2014, p. 3). Key messages from the 2007 series were that mental health is neglected and connected with many other conditions of global health importance; resources for mental health are inadequate and unevenly distributed, particularly in LMICs; there is a strong evidence base for effective mental health interventions that could be scaled up; it is crucial to learn from past successes and failures; and finally, there is a need for indicators to measure progress at country level (Horton, 2007). A year after the 2007 Lancet Series on Global Mental Health, progress in the field was assessed. The conclusion was that although no substantial measurable outcomes could be seen after just one year, awareness of and commitment to the field among key stakeholders had increased (Patel et al., 2008). The progress continued in the years to follow, summed up in the 2011 Lancet Series on Global Mental Health (Patel, Boyce, Collins, Saxena, & Horton, 2011). From 2007-2011 several global initiatives on mental health were launched, such as the WHO Mental Health Gap Action

Programme Intervention Guide (mhGAP-IG), the Grand Challenges in Global Mental Health and the Movement for Global Mental Health (Collins et al., 2011; Patel, 2012; Patel, Boyce, et al., 2011; Patel, Collins, et al., 2011; WHO, 2008). Adding to this, at country level there had been policy developments, plans to scale-up care and growth in the evidence base for successful interventions and treatment. It was, however, noted that there was still a long way to go, and there were major issues that needed to be addressed. First, the human rights of people with mental disorders, particularly linked to freedom, dignity and the right to appropriate care. Second, the need to scale-up mental health care, and the necessary budgetary allocations and local adaptations for this to happen. Third, the evidence base on delivering effective treatments in real world contexts was still weak. Fourth, the importance of including mental health issues in the emergency response to natural disasters and conflicts (Maj, 2011; Patel, Boyce, et al., 2011). The progress has continued also since 2011, but the gaps, shortages and abuses in policy, service delivery and human rights continues (Becker & Kleinman, 2013).

The field of global mental health pays attention primarily to the complex and challenging mental health needs of people living in LMICs, where the gap between the need for mental health services and available services is particularly large, and the majority of people with mental disorders are untreated (Gureje & Stein, 2014; Thornicroft, 2007; Tomlinson, 2013). The global mental health movement has supplied ample evidence of these treatment gaps (Burns, 2011; Hanlon, Fekadu, et al., 2014; Pillay & Lockhat, 1997; Raviola et al., 2011; Saraceno et al., 2007; Saxena, Thornicroft, Knapp, & Whiteford, 2007; Swartz, 2007; Thornicroft, 2007). It is also clear that substantial progress has been made in developing an evidence base for innovative treatments which have been shown to work in low-income contexts. Despite these improvements, and while there is now good evidence of cost-effective mental health interventions, there is as yet little evidence of how to implement these in real-life settings, beyond a few identified in innovative recent studies (Eaton et al., 2011; Hanlon, Fekadu et al., 2014; Patel, Araya et al., 2007; Patel, Boyce et al., 2011; Patel & Stein, 2015; Patel & Thornicroft, 2009; Thornicroft & Patel, 2014). It is crucial that interventions are contextually appropriate, incorporating medical pluralism and adapted to local explanatory models for mental disorder (Hanlon, Fekadu et al., 2014). The questions at stake are far broader than simply those of scale-up of transportable technologies; they involve issues of cultural contexts, health system challenges, and interfaces between seemingly incompatible sets of demands and needs. In overburdened health care settings far removed from centres where there is a critical mass of expertise around mental health, mental health issues often continue to be seen as ephemeral and unimportant. Adding to this, it is important to recognise that many, if not most, people suffering from mental disorders primarily rely upon self-care or the non-

professional sectors of care, such as religious institutions, traditional healers, family and friends (Hanlon, Fekadu et al., 2014).

In 2008 WHO developed the WHO Mental Health Gap Action Programme Intervention Guide (mhGAP-IG) (WHO, 2008). The guidelines are built on evidence-based interventions suggesting that primary care providers can be trained to deliver mental health services for the most common mental disorders under the supervision and guidance of trained and/or specialist mental health providers. Scaling-up is said to be best done in a joint collaboration between governments, health professionals, civil society, communities and families, supported by the international community (Gureje & Stein, 2014; WHO, 2008). Furthermore, in 2012 WHO developed the WHO QualityRights tool kit, aiming to support governments to asses and improve the quality and human rights of the country's mental health and social care facilities. The tool kit suggests a move from in-patient facilities to community based mental health care. It is further suggested that the United Nations Convention on the Rights of Persons with Disabilities be used as a basis for human rights standards to be upheld in all mental health care (WHO, 2012). Building on the mhGAP-IG, in 2013 WHO World Health Assembly adopted the Comprehensive Mental Health Action Plan to protect, promote and respect the rights of people with mental disorders in line with international and regional human rights instruments (WHO, 2013c). The plan outlines four main policy actions for mental health; strengthening leadership and governance for mental health; providing comprehensive, integrated, and responsive community based mental health and social care services; implementing strategies for promotion and prevention in mental health; and strengthening information systems, evidence and research on mental health (DeSilva, Samele, Saxena, Patel, & Darzi, 2014; WHO, 2013b). Challenges to implementing the suggested mental health policy actions in LMICs include lack of priority and investment for mental health, challenges integrating mental health into primary health care services (due to lack of human and financial resources) and lack of evidence on effectiveness and cost of scaling-up interventions (DeSilva et al., 2014).

A major challenge for the field of global mental health is that around 90% of the research in the field of mental health is from the West, and there is a dire need for action in the so-called global south (LMICs), making up 90% of the global population. For action to take place now, one must assume that knowledge from the West is applicable, or easily translated to the diverse contexts of LMICs. Furthermore, most experts in the field are trained in the West. It has been argued that there is a need for research and innovation in this field that takes cultural variations into consideration, as this has generally been ignored in previous research on evidence-based practice for mental disorders (Kakuma, Minas, & Dal Poz, 2014; Kirmayer & Swartz, 2014; Prince, 2014). There is a call for a more culture-centred approach to mental health care by scientific medicine, and increased collaboration between scientific and

traditional systems of care and healing in an attempt to improve patient care (Campbell-Hall et al., 2010). An essential question posed by Mills (2014) is what role psychiatry should play in responding to mental disorders or mental distress worldwide. Is it simply a question of scaling-up available psychiatric drugs and therapies, as called for by WHO and the Movement for Global Mental Health (MGMH)? Such interventions are largely developed and tested in the West, and their applicability in a non-Western context can thus be questioned. Alongside the call to scale-up psychiatric interventions are calls to abolish psychiatric diagnostic systems and acknowledge harm caused by some psychiatric interventions. In fact, psychiatry is increasingly criticised in many high-income countries due to its somewhat questionable evidence-base, making it relevant to ask if it is appropriate to export such interventions to other parts of the world (Mills, 2014). While I acknowledge that such debates exist, it is outside the scope of this dissertation to study the appropriateness and effect of psychiatric interventions in LMICs.

2.4 Concluding statement

Two key concepts will be used throughout this dissertation, namely the concepts of psychosocial disability and care.

The framework for psychosocial disability adopted in this dissertation is based on the bio-psycho-social model (WHO, 2001b). From this point of view, psychosocial disability is constructed at the interplay between mental disorder, individual, cultural and contextual characteristics. This includes the physical, economic and cultural environment where people live, and their own and other's attitudes and behaviours to stigma and discrimination. I apply a critical approach to mental disorder and psychiatry, recognising that while there may be some universal features to mental disorders, there are differences in the expression of and responses to mental disorders. Thus, diagnostic categories cannot be assumed to have the same meaning and validity across all contexts. Difference and diversity in the experience and expression of psychological phenomena are rooted in social-developmental processes, such as interactions in the local social environment, including family, community and other networks, as well as broader social phenomena of power and control, such as colonialism, the global economy and the economic power of multinational drug companies. In this dissertation, I will focus less on clinical diagnosis and treatment of mental disorders and more on social, cultural and individual aspects of mental disorder, access to appropriate care and human rights of people with psychosocial disabilities. I mainly use the term psychosocial disability. This is, however, not a commonly used lay-term, and I found throughout my data collection that the term mental illness was the most commonly used and understood, while the literature commonly uses the term mental disorder. In people's stories and in direct quotes I will therefore use the terminology that they used themselves.

In this dissertation the care concept is approached from a broad perspective to include various forms of activities and structures aimed at meeting the needs of ourselves and others. This includes scientific medicine, traditional health care, family care, community care and so on. It not only includes activities of treatment and healing, but also activities that directly or indirectly impact on a person's mental health, such as occupational participation and inclusion.

In the next chapter I will explore the empirical evidence on care for people with psychosocial disabilities.

Chapter Three: Care for people with psychosocial disabilities – Overview of empirical evidence

3.1 Chapter outline

This chapter will give an overview of key aspects of the evidence on care for people with psychosocial disabilities. In Chapter 3.2 I will give a brief overview of the literature on access to health care for people with disabilities. While there is extensive literature on care for people with disabilities in general, in the following sections of this chapter I will narrow the scope and focus on psychosocial disability more specifically. I will first give a general introduction to care in LMICs, before I move on to describe care practices for people with psychosocial disabilities in Africa in general, and in South Africa in particular.

3.2 Access to care for people with disabilities

People with disabilities have the same health care needs as everyone else, and in addition to this many have specific health care needs related to their disabilities (Shakespeare et al., 2009). These are often complex needs, and without proper care individuals with disabilities are at risk of not realising their full potential and full participation in society (Hwang et al., 2009; Stein, Stein, Weiss, & Lang, 2009). Several studies have shown that despite the complex medical and non-medical needs of people with disabilities, they experience multiple barriers in accessing appropriate, good quality health care, and the situation is particularly critical in LMICs (Hwang et al., 2009; Stein et al., 2009; Tomlinson et al., 2009). Consequently, people with disabilities have poorer health outcomes than people without disabilities (Tomlinson et al., 2009). Barriers to accessing health services range from structural/environmental barriers (physical and social environment), procedural barriers (health provider and health facility) and attitudinal barriers (Hwang et al., 2009; Smith et al., 2004). People with disabilities residing in rural areas face more barriers in accessing appropriate health care due to lack of qualified personnel, necessary expertise, facilities, and equipment (Lishner et al., 1996). Despite increasing amounts of empirical evidence on these issues, there is a call for more research on barriers to accessing health services for people with disabilities, strategies to integrate the needs of people with disabilities into primary health care and ensuring local delivery of health care (Tomlinson et al., 2009).

Shakespeare (2014) argues that "human beings are not all the same, and do not all have the same capabilities and limitations. Need is variable, and disabled people are among those who need more from others and from their society" (Shakespeare, 2014, p. 90). Because of their often many, multifaceted and complex health care needs, individuals with disabilities often

seek care from a wide range of health providers (Lawthers, Pransky, Peterson, & Himmelstein, 2003; Officer & Groce, 2009), and the lack of appropriate coordination between these providers is a commonly reported problem (Lawthers et al., 2003; Stein et al., 2009). Thus, there is need for more flexible and multi-disciplinary approaches in the delivery of health care to people with disabilities (Lawthers et al., 2003).

Key elements to achieving the goals of providing equal access to health services for people with disabilities, as set out in the UNCRPD, are patients' empowerment, self-determination, and community inclusion (Stein et al., 2009). It has been argued that people with disabilities in general, and people with intellectual and psychosocial disabilities in particular, must be assisted to achieve self-determination, to manage their own lives and have control over decisions that affect their lives (Strnadová, 2015). Many care givers are so focussed on the vulnerability of those they care for that they forget to nurture their self-determination and empowerment, and as a result compromise real participation (Strnadová, 2015). A facility directed health care system is thought to provide poorer quality care than a consumer-directed health care system, especially when it comes to delivering appropriate care for individuals with disabilities (Hwang et al., 2009). There is evidence to suggest that self-efficacy in health care has positive effects on subjective and objective health indicators. For people with disabilities this means increased participation in health care decisions to enable more informed choices (Hwang et al., 2009). Health providers' assumptions and attitudes towards disability often lead to inappropriate, poor and sometimes dangerous treatment of individuals with disabilities in the health system (Braathen et al., 2015; Shakespeare et al., 2009). Shakespeare and colleagues (2009) emphasise the importance of approaching people with disabilities with the same respect for their autonomy and dignity as with all patients. To do this one must communicate directly with the disabled individual, and not just through proxies or interpreters. It is also important for health providers to understand that individuals with disabilities can be healthy, and that not all their health care needs are disability related (Shakespeare et al., 2009). The need for support goes beyond assistance with daily living tasks, and includes the desire for companionship, conversation and togetherness, through relationships of intimacy and friendship. People with disabilities have the same needs as any other human being in this regard. But it is problematic to artificially create these relationships, as friendship and intimacy are natural, mutual and genuine human relationships, which cannot be constructed or paid for. This puts people with disabilities at risk for isolation (Shakespeare, 2014).

Diagnosis is essential for the construction and understanding of disability, and is for many the crucial moment when they are inscribed with a disability, which legitimises them to claim certain rights, supports or benefits. It has also been argued that diagnosis can be a form of oppression or labelling (Shakespeare, 2014). It is often believed that identifying the cause is crucial for

finding a permanent cure for disability, while treating only the symptoms will give temporary, but not permanent, relief (Whyte & Ingstad, 1998). In African folk medicine it is commonly believed that disability is caused by spirits, witches, ancestors, and so on, who are punishing the disabled individuals and/or their families for social and moral wrongs committed by them. Thus, help must be sought from the powers responsible for the problems, and the medium for this is a variety of traditional healers who, for instance, work to eliminate pollution, counteract witchcraft, make offerings to spirits or communicate with ancestors (Braathen & Ingstad, 2006; Braathen et al., 2015; Ingstad et al., 2012; Whyte & Ingstad, 1998). But many disabling conditions cannot be cured, not by professional health care and not by healers in the folk sector. In these circumstances people often speak of disability as "the work of God", something that no humans, spirits, witches, ancestors, and so on can alter (Braathen & Ingstad, 2006; Whyte & Ingstad, 1998).

It is commonly assumed that people with disabilities are maltreated; abused, neglected or even killed, by their families to conceal their existence (Ingstad, 1999; Whyte & Ingstad, 1998). In-depth studies into these phenomena, however, have shown that most families do their best to care for their disabled family member. But, living in poverty, with few household resources, families are often unable to provide the assistance and attention necessary for optimal participation, care and inclusion of the disabled family member (Braathen & Ingstad, 2006; Braathen et al., 2016; Muderedzi & Ingstad, 2011; Whyte & Ingstad, 1998).

Across the world, most of the care provided to people with disabilities both in childhood and adulthood is provided by their families. Their contribution is an invaluable, but often overlooked, aspect of care. For many families caring for a disabled family member places enormous burdens on individual family members and on the family as a whole. The burdens are exacerbated by poverty and lack of resources. Despite this, there is a lack of much needed support for these care givers, and lack of attention to this field of research (Braathen et al., 2016; Levin, 2006; McConkey, 2016; Sandy, Kgole, & Mavundla, 2013; Viana et al., 2013).

3.3 Care in low and middle-income countries (LMICs)

3.3.1 Mental health policy and human rights

There are grave inequalities in mental health across the world. Generally, high-income countries have substantially more and better legislation and resources for mental health compared to low-income countries (WHO, 2015), which reflects the overall priority for mental health issues in the different countries. Factors attributed to the inequalities are uneven development, colonialism, exploitation and globalisation (Kirmayer & Swartz, 2014). Empirical evidence on social determinants of mental health supports the call to scale up mental health

services as a public health, human rights and development priority (Chisholm et al., 2007; Lund et al., 2011; Lund et al., 2014; Sorsdahl et al., 2011; WHO, 2010a). There is scarce evidence on effective interventions to break the possible negative cycle of mental disorder and poverty. Existing evidence suggests that mental health interventions are associated with positive economic outcomes, but there is no conclusive evidence that poverty alleviation programmes lead to improved mental health (Lund et al., 2011).

Mental disorders are often associated with violations of human rights, especially in relation to the treatment of people with mental disorders at home or in the community in contexts with few mental health resources and knowledge. It has been argued, however, that most violations of human rights for people with mental disorders happen in psychiatric interventions and treatment (more specifically forced institutionalisation, chaining, cage beds, etc.). Psychiatry has been accused of being colonising, both when it is applied in contexts from which it originates and when it is applied in non-Western contexts (Mills, 2014). In ensuring the human rights of people with mental disorders, a number of requirements must be met. First, access to professionals who can recognise and diagnose their disorder is essential for correct diagnosis and initiation of appropriate treatment. Second, access to appropriate interventions to deal with the disorder, adjusted to the individual and the local context, in a setting that is decent, humane and non-abusive. This requires more specialised personnel, in addition to task-shifting, community and family-based care. A fundamental human right of people with mental disorders is to live a full affective and social life (Maj, 2011).

The UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) is a step in the right direction of addressing human rights abuses against people with mental disorders, but for it to have a real impact, actions must be made at societal, community and family level (Cohen et al., 2014).

3.3.2 Scientific health care

Across the world the distribution of mental health professionals, such as psychiatric nurses, psychologists and psychiatrists, is highly unequal. For instance, in high income countries there are an estimated 50 mental health professionals per 100, 000 people, while in low-income countries there is 1 (WHO, 2015). Given the overwhelming evidence on the lack of mental health specialist resources in LMICs, it is generally agreed and recommended that services should be delivered in the non-specialist primary health care system, which is also where most people seek services (Chisholm et al., 2007; Gureje & Stein, 2014; Hanlon, Luitel et al., 2014). Despite this, most mental health spending globally is designated to psychiatric institutions (WHO, 2015). In recent history psychiatry, through institutional care, has been the norm, previously referred to as mental asylums, and more recently as psychiatric institutions.

Through European colonisation in Africa and Asia, these institutions became the main feature of mental health care in both colonised and non-colonised countries in these parts of the world. Towards the end of colonialism doubts about the efficacy of institutional care for mental disorders began to appear, and as a result psychiatry in Western Europe and North America started to move away from institutional care, towards office-based practices and community based mental health systems. Despite this change in the Western world, psychiatric hospitals have continued to dominate mental health care in many LMICs (Cohen et al., 2014; Mills, 2014; Saxena, Thornicroft, Knapp, & Whiteford, 2007; WHO, 2012).

Across the world, nurses constitute the most prevalent professional group working in the field of mental health. In LMICs most health care at primary level, including mental health services, is delivered by nurses (Ghebrehiwet & Barrett, 2007; WHO, 2015). Despite this, few nurses have the necessary expertise to recognise, diagnose and treat mental disorders, and nurses in LMICs generally have lower levels of mental health training than nurses in HICs. There is also a general shortage of nurses in most LMICs, and with the low priority for mental health in these countries, shortage of nurses in that sector is even more acute (Ghebrehiwet & Barrett, 2007). In an attempt to scale-up mental health services in LMICs, inclusion of nurses is said to be essential, but scale-up will require task-shifting and a redefinition of the roles of specialist personnel (Ghebrehiwet & Barrett, 2007; Patel, Boyce et al., 2011). Studies of task sharing and task-shifting in mental health services in LMICs have found that they are perceived to be acceptable and feasible by service providers, users and community members. There are, however, key conditions that need to be met for successful implementation; there is a need for more human resources and medication, supervision and support at all levels of care, and training and compensations for all involved health workers. Adding to this, interventions must be adapted to local and cultural realities (Maselko et al., 2015; Mendenhall et al., 2014; Mwape et al., 2010; Petersen, Lund, & Stein, 2011).

Several mental disorders have well documented biomedical treatment options, but their successful treatment is dependent on accurate diagnosis. In LMICs, however, most mental disorders are not diagnosed, and thus not treated, contributing to disability and stigma (Akyeampong, 2015; Maj, 2011). Upon providing a diagnosis, mental health professionals need to not only provide patients with mental disorders factual information about their diagnosis, but also talk to the patients about the social consequences of having such a diagnosis. Information must be provided to the patients in an acceptable and accessible way. Generally, mental health providers must provide more accurate, clearer and detailed information about diagnosis and treatment to both patients and their families. This includes being aware of common misconceptions about the particular diagnosis, and undermining these. This can, for instance, be that patients are responsible for acquiring mental disorders

and thus can be blamed. There is evidence that there is less stigma attached to conditions that happen to people through no fault of their own (Thornicroft, 2006). It has been suggested that developing information packs for patients and families about what mental disorders are and are not could be a good strategy to address mental health stigma, experience and treatment. The information packs should address common myths and beliefs about mental disorders, and undermine these, providing nuanced and correct information. Such information packs are not widely available and used today (Thornicroft, 2006).

Communication is an essential, but often overlooked, feature of mental health services. Practitioners in the field are often unable to communicate directly with recipients of services due to language barriers, which in turn can reduce the validity of the service. Clinical mental health interpretation is a skilled task, but much interpretation is done by unskilled family members or personnel at health facilities (Kirmayer & Swartz, 2014; Swartz, Kilian, Twesigye, Attah, & Chiliza, 2014). As a result, interpretation errors are commonly made, such as leaving out key material, contraction and summarizing of information, mistranslations and adding material not mentioned. There are also other challenges related to interpretation, such as what role the interpreters should take on, for instance, as neutral translators without opinions or views (which it is argued is almost impossible), patient advocates, or co-clinicians. Inevitably, there are limitations to translation, and one can never have completely accurate translations across languages and cultures. There are, however, ways of working that limit translation mistakes. The key feature to that is for the interpreter and the clinician to be aware of and understand the complexities and inevitable challenges of interpretation, to communicate about them, and work together as a team to minimise translation mistakes. Having said that, language and cultural barriers cannot be completely overcome in any clinical practice, and thus it is essential for the clinician to be open for alternative interpretations and approaches (Kirmayer & Swartz, 2014).

Ideas of recovery vary across cultures and social context, and have been divided into the following categories: clinical recovery (symptom severity, treatment adherence, rehospitalisation), existential recovery (hope, emotional well-being), role functioning (employment, housing), physical functioning (physical health and activity) and social relationships and organisation (support, integration) (Kirmayer & Swartz, 2014). It is essential to understand the experience and explanatory models of patients with mental disorders to inform epidemiological research and health policy and planning. Particularly, community based mental health care should have this at the core to ensure their cultural and contextual appropriateness (Lund & Swartz, 1998). Acknowledging the importance of culture in mental health has implications for research, training and practice. There is a need for research on different cultural, traditional and knowledge systems, through a process of dialogue and co-

learning between these different systems. This means studies and interventions beyond those scaling-up best-practices developed in the wealthy, urban, culturally distinct countries of the North and West, but also focusing on models emerging from other local and cultural practices. There is also a need for better cultural adaptation of diagnostic, treatment and preventive systems. To achieve this there is a need for more bottom-up strategies, listening to diverse local needs in combination with already developed and tested best-practices. Exploring cultural feasibility and acceptability of available interventions, strategies and practices (Kirmayer & Swartz, 2014; Kleinman, 2004; Kohrt, Mendenhall, & Brown, 2015).

> Local strategies may not always be optimal and good ideas, and approaches from other places should be widely disseminated. However, it remains important that interventions take local cultural values and perspectives seriously into consideration to ensure the protection and expression of cultural identity and community. Ultimately, this demands pluralistic civil societies, to which mental health services can contribute. (Kirmayer & Swartz, 2014, p. 57)

The past few decades has seen increased recognition and interest in cultural and contextual adaptation of mental health interventions. Adaptations range from simple translation/reformatting of intervention to fit local languages and examples, to changes in methods and goals to fit local cultures and contexts. In making appropriate adaptations and ensuring the effectiveness of interventions, a number of factors should be considered, for instance local values, modes of community solidarity and social support, available resources and practical considerations (Kirmayer & Swartz, 2014). There is a need for evidence on risk factors for mental disorder across cultural settings, as well as on approaches of traditional healers to deal with these disorders across settings (Hanlon, Fekadu et al., 2014).

3.3.3 Community based care

In the field of global mental health, the main priority has been to scale-up evidence based interventions in LMICs, which have largely been developed in high-income countries. Recently, however, the field has seen a shift towards community based approaches, including self-help and peer-support. Approaches that are socially and culturally informed; emerging from the local context in which they occur, focussing on experiences and expertise of those living with mental disorder, based on local priorities and using community resources (Kirmayer & Pedersen, 2014; Mills, 2014).

Community based mental health services (CBMHS) have been developed as a result of deinstitutionalisation, with the realisation that people with mental disorders would need social and rehabilitation services in addition to medication to function well in their local communities.

CBMHS have proven to be at least as effective as hospital-based mental health services. In more recent years CBMHS have increased in popularity in LMICs, and there is general agreement that a move towards more community based mental health care would be the best (Cohen et al., 2014; Mills, 2014; Saxena et al., 2007; WHO, 2012). Despite this, there are substantially less community based mental health services in LMICs than in high-income countries (Ghebrehiwet & Barrett, 2007). Studies have found that there are major challenges to the successful implementation on CBMHS, such as lack of funding, technical expertise and human resources (Cohen et al., 2011). It is essential that both skilled, semi-skilled and un-skilled health workers receive adequate training, support and compensation to ensure sustainability and avoid exploitation (Chisholm et al., 2007; Kalofonos, 2015).

Historically, care for people with mental disorders has been the responsibility of families, but there are also early accounts of help and support seeking from religious and spiritual institutions (Cohen et al., 2014). Non-formal resources like community and home based support systems, using unskilled or semi-skilled health workers, have great potential for contributing to mental health advocacy and service delivery, and can play an important role in addressing the mental health treatment gap (Chisholm et al., 2007; Kalofonos, 2015; Saraceno et al., 2007). Local, indigenous methods of care and healing can have personal and social functions in addition to their therapeutic efficiency. There is, however, broad consensus in the field of global mental health that the most severe mental disorders are best treated with psychopharmaceuticals, while milder cases of mental disorder and many common mental disorders benefit more from interventions based on lifestyle changes, social support and coping methods. A combination of the two, not disregarding the importance of community based approaches, has been shown to be the most beneficial (Kirmayer & Pedersen, 2014).

3.3.4 Medical pluralism

Across the world there is a lack of mental health facilities and professionals, and it is widely acknowledged that there will not be enough professionals in the foreseeable future to respond to the wide range of problems categorised under mental disorder. As such, there is a need to think of alternative models for mental health care, outside the immediate professional mental health care system. Such models may include the use of primary care clinicians, community mental health workers (with less training), or collaboration with indigenous healers, religious institutions and other systems of care and support (Kirmayer & Swartz, 2014; Okello & Musisi, 2015). Adding to this, a multi-sectoral approach is an important step towards recovery from mental disorders, which is dependent on more than just clinical care, but also includes employment, social networks, income, social status, confidence and a feeling of social value (Thornicroft, 2006). Mental health issues should be addressed in a holistic manner, including

structural and socioeconomic issues as well as clinical treatment (Kalofonos, 2015). The overall evidence suggests that mental health care should be integrated into general health care at all levels of the health system, from community based health care, to specialist health care. In many contexts and for some mental disorders there may be a need for community sensitisation and case-finding, as there is little tradition for help-seeking for some mental disorders (Prince et al., 2014).

Scaling up mental health promotion and prevention requires a multi-sectoral approach, involving policy makers, civil society and service providers (Petersen, Barry, Lund, & Bhana, 2014; Saraceno et al., 2007). It is essential to target social (access to food, water, land, energy, oppressive regimes, armed conflict, alcohol/ narcotics, socioeconomic inequality, employment, work conditions, social protection) and environmental (toxins, micronutrient deficiencies, communicable diseases, head injuries, birth complications) determinants for mental health. Furthermore, empirical evidence shows that early interventions targeting children and youth have the greatest preventive effect. Examples of such interventions are parenting skills training and socio-emotional learning programmes (life-skills programmes) (Patel, Flisher, Hetrick, & McGorry, 2007; Petersen, Barry et al., 2014).

The importance of collaboration with and integration of traditional systems of medicine in primary care has been acknowledged in the Alma Ata Declaration (WHO, 1978a). This collaboration, however, is not without challenges, given the often vastly different explanatory and treatment models in the different systems of medicine and care. As such, in most settings, collaboration is more realistic than integration of different care systems. The risk with such collaboration is that the most powerful system of biomedicine will undermine local forms of healing that may in fact provide important meaning and support to patients. On the other hand, recognition of local forms of healing by biomedicine may give it more legitimacy (Kirmayer & Swartz, 2014; Okello & Musisi, 2015). The importance of building relationships with local authorities, such as elders, leaders and traditional healers, has also been highlighted as a key feature to successful implementation of contextually appropriate mental health interventions. This may also include participation in community activities to build mental health literacy and awareness (Zinck & Marmion, 2011).

A review of strategies for mental health care in LMICs found that there is a lack of studies and interventions focussing on inter-sectoral approaches to mental health care. One of the identified studies highlighted the effectiveness of teachers in raising awareness about mental disorders among children, parents and neighbours. In many LMICs people seek help from alternative or traditional practitioners before the professional health care system, but

evaluation studies on the role of these alternative treatment forms or other community resources in prevention of mental disorder and care are scarce (Kakuma et al., 2014).

3.3.5 Help-seeking

Mental health literacy has been found to be low in many LMICs (Hanlon, Luitel, et al., 2014; Petersen, Lund et al., 2011). A WHO survey in 24 low, middle and high-income countries found that the major barriers to initiating and continuing mental health treatment (scientific medicine) for people with mild and moderate common mental disorders were attitudinal and low perceived need. This is closely linked to low mental health literacy. People wish to handle their own problems without seeking help, and many do not believe that scientific medicine is effective in treating mental disorders. Also, many reported dropping out of treatment because of negative experiences with treatment providers. Structural barriers were also reported, but primarily among respondents with severe mental disorders. Thus, in addition to addressing the structural barriers to mental health care, it is important to increase mental health literacy (Andrade et al., 2013).

A systematic review on the feasibility and acceptability of psychosocial interventions for schizophrenia in LMICs found some evidence suggesting acceptability of these interventions, but very limited evidence to suggest feasibility. Major barriers highlighted in the literature were stigma associated with having a mental disorder, and difficulties engaging family care givers in interventions. Despite the wide recognition of cultural and contextual factors in the field of Global Mental Health, these were largely ignored in most of the studies included in the review. Research in this field has largely studied effectiveness of interventions, and not their feasibility and acceptability (Brooke-Sumner et al., 2015).

3.3.6 The future of mental health care in LMICs

Despite the high disease burden of mental disorders, the global mental health field has not achieved the visibility, attention, funding and priority it should (Tomlinson & Lund, 2012). Many have argued that development in the field has been too slow, and despite studies proving the effect of evidence-based mental health interventions in LMICs, the scale-up progress is slow compared to scale-up of interventions in the field of global health (Kleinman, 2013b). The slow progress could be linked to the debate around the definition of mental disorder and the impact of stigma on mental disorder and its management, which again can lead to low priority for mental health at policy level, resulting in lack of funds and resources (Kleinman, 2013b; Tomlinson & Lund, 2012).

The field of global mental health faces both challenges and opportunities in the future. The increased interest in the field has led to more funding and resources for research, capacity building and service development in LMICs, with great potential benefits. However, there are also barriers to progress in the field, such as lack of resources (human, financial and technical), gaps in knowledge (especially on issues of aetiology, treatment and cultural variations) and human rights abuses of people with mental disorders (Cohen et al., 2014; Saxena et al., 2007). Resources for mental health are inadequate in most countries. In LMICs, in particular, there is a critical need for more infrastructure and human resources in this field, in addition to appropriate policies, legislation and increased economic investment (Chisholm et al., 2007; Eaton et al., 2011; Jacob et al., 2007; Kakuma et al., 2014; Ritsuko Kakuma et al., 2011; Maulik, Daniels, McBain, & Morris, 2014; Petersen, Barry et al., 2014; Saxena et al., 2007; Tomlinson, 2013). The shortage of mental health workers will persist or even worsen unless investments are made to train a wider range of mental health workers. Task-shifting and expanding services into the contexts of primary and community health care could be effective and feasible approaches to address this problem, but they will require investment, innovative thinking, good leadership and effective supervision. A broad range of workforce categories from various sectors included in mental health care in LMICs would facilitate the much needed scaling-up of mental health services. The composition of workers should take into consideration contextual and cultural factors, and be aligned with the existing health care system (Chisholm et al., 2007; Eaton et al., 2011; Kakuma et al., 2014; Kakuma et al., 2011; McInnis & Merajver, 2011). There is a lack of research focussing on human resources for mental health in LMICs, which is critical to develop effective strategies for mental health in these contexts. Furthermore, evidence is lacking regarding strategies for cost-effective community based mental health care (Kakuma et al., 2014). Patel (2015) sums up what he thinks should be key priorities for the field of Global Mental Health in the future:

> Much of the recent academic and programmatic focus in global mental health has been on the implementation of evidence-based interventions for mental illness, particularly in low-resource settings. Optimizing the acceptability and feasibility of the implementation of these interventions, and enhancing their effectiveness, require them to be exquisitely sensitive to contextual factors, especially cultural and social influences on mental health. It is crucial that they can be delivered by available human resources, typically involving task-shifting to community health workers or lay people. (Patel, 2015, p. 8)

3.4 Care in an African context

3.4.1 Mental health policy

Mental health policy remains weak or non-existent in many countries throughout Africa (WHO, 2015). The low priority for mental health issues has been attributed to lack of knowledge, stigma, low prioritisation by governments and donors and low grassroots demand. Adding to this there is insufficient empirical evidence and consultation with user groups to inform policies, plans and programmes. Finally, policies are poorly operationalised and disseminated. The result is that mental health services are largely unavailable or insufficient (Omar et al., 2010).

3.4.2 Scientific health care

Despite a recent shift towards medical pluralism on the African continent, psychiatric practice remains influential, for instance with the wide adoption of the DSM over the past few decades. Lunatic asylums were introduced to the continent during the colonial period, with the assumption that people with mental disorders were dangerous to the general public, and thus needed to be removed from public places. As such, the asylums were holding places more than places for care and cure (Akyeampong, 2015). Today the African continent faces large unmet needs for diagnosis and treatment of mental disorder, and poor access to health services in general and mental health services in particular (Chibanda et al., 2016; Daar et al., 2014; Patel & Stein, 2015). In most African countries today there is a lack of trained mental health personnel, such as psychiatrists, psychologists and psychiatric nurses. Mental health care has a low priority in most African governments, and is as such highly underfunded and poorly staffed (Akpalu et al., 2010; Akyeampong, 2015; Chibanda et al., 2016; Daar et al., 2014; Okello & Musisi, 2015). Despite the variety of possible care options, pharmaceuticals remain the most accessible for most patients, but there is very limited access to appropriate pharmaceuticals for this patient group. In addition, there is a lack of qualified personnel to subscribe and dispense such medication, and lack of follow-up. There is also lack of funding to develop and implement mental health policies, and lack of localised knowledge on effective treatment options, both using scientific and traditional medicine and care (Daar et al., 2014; Ofori-Atta, Read, & Lund, 2010; Raja, Wood, & Reich, 2015).

An anthropological study from communities in rural Ghana found that despite health worker's views that people in the community had little awareness of biomedical treatment for mental disorders, most of the informants had sought help from psychiatric services, and had received antipsychotic medication. The patients found that the medication had positive effects, such as controlling aggression, inducing sleep and reducing perception experiences, like visions. Despite this, many discontinued their use because of side-effects such as weakness and

drowsiness, which were seen as conflicting with notions of health, which is closely linked to strength and productivity (ability to work). The side effects were in many ways experienced as more disabling than the symptoms of the disorder itself (Read, 2012).

3.4.3 Traditional healing

WHO (2013d) uses the following definition for traditional medicine:

> Traditional medicine is the sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness. (WHO, 2013d, p. 15)

A traditional healer has been defined as:

> …a person who is recognized by the community in which he lives as competent to provide health care by using vegetable, animal and mineral substances and certain other methods based on the social, cultural and religious background as well as on the knowledge, attitudes and beliefs that are prevalent in the community regarding physical, mental and social well-being and the causation of disease and disability. (WHO, 1978b, p. 9)

“Traditional healer” is an umbrella term for a number of practitioners, such as diviners, herbalists, midwives, circumcisers, faith healers and traditional birth attendants. Traditional healers share the language, culture and history of their patients, are located within most communities and villages throughout Africa, and as such they are well positioned to provide primary health care (Okello & Musisi, 2015). Traditional healers have no formal training, but acquire their knowledge from other healers (often passed on within families), from spirits of deceased family healers or through callings from ancestral spirits (often referred to as *ukuthwasa* – see Chapter 2.2.2). Many traditional healers have become healers after receiving such a calling, often in the form of illness, through dreams, visions, hallucinations, nonconformist behaviour, lack of concentration, or through events of misfortune affecting the individual or his/her family (Okello & Musisi, 2015). Okello and Musisi (2015) argues that traditional healers take on a more holistic approach to health compared to scientific medicine. They look at the whole person, mind and body, and they also consider the family and community surrounding the individual. Illness is thus seen as more than a malfunctioning organ; it is a disruption to everyday life. A holistic approach can facilitate healing and alleviate stress, which is an essential part of mental health care. Furthermore, when patients have faith in the healing powers of the practitioner and medicine, this also facilitates the healing process

(Okello & Musisi, 2015). Traditional medicine is a large body of knowledge passed on for centuries. Many of our modern scientific drugs were discovered from their use in traditional medicine. This is true, for instance, of a number of herbs used to treat mental health problems, such as St. John's wort for depression, kava for anxiety, and ginkgo biloba for dementia (Okello & Musisi, 2015).

Traditional healers are an essential part of the total health care system in Africa. For approximately 80% of the African population, most of them living in poor rural communities, traditional healers serve as primary health care providers (Okello & Musisi, 2015). People choose to use traditional healers to deal with mental health problems for a multitude of reasons. Primarily, traditional healers are culturally appropriate. They share the same explanatory models for mental disorder as their patients, and within this belief system scientific medicine is commonly not seen as suitable to treat these disorders. Adding to this, traditional healers outnumber practitioners of scientific medicine, and they are located within almost every African village (Ae-Ngibise et al., 2010; Okello & Musisi, 2015; WHO, 2013d). WHO (2013d) estimates that in Africa the ratio of traditional healers to the population is 1:500, while the ratio of medical doctors to the population is 1:40 000. In such contexts traditional healers often become people's primary source of health care (WHO, 2013d). As such the traditional healers are culturally appropriate, available and accessible, and adding to this many healers are also affordable and flexible. They are affordable, not in the sense that they are cheaper than scientific medicine, but in that they are more flexible in how they accept payment, for instance, in the form of livestock or other goods instead of money. They are also flexible in the way they communicate and collaborate with other traditional healers who provide different kinds of traditional medicine and treatment, as well as with scientific medicine (Ae-Ngibise et al., 2010; Okello & Musisi, 2015).

Although a large proportion of the African population rely on traditional medicine, the practices are illegal in many African countries. Even in countries where they are legal, there is very little regulation. Where the practices are illegal, these laws are not enforced, and traditional healing practices remain widespread (Okello & Musisi, 2015). Adding to this, collaboration between scientific medicine and traditional healers in the field of mental health is underutilised (Hanlon, Luitel et al., 2014).

3.4.4. Family care

In a Sub-Saharan African context, and more specifically in the context of Ubuntu, family care is often more common than institutional care. The majority of the care burden is placed upon the family, usually the women in the family (Evans & Thomas, 2009), but Evans and Thomas (2009) found that in the absence of women, boys and men also got involved in care work.

African health policies and health institutions endorse the family as the dominant care provider, and to a large extent see care as the responsibility of the family (Evans & Thomas, 2009). In their study on care in the UK, Namibia and Tanzania, Evans and Thomas (2009) found that gender norms, generational power, family relationships and socio-cultural expectations are closely linked to caring relations and responsibilities (Evans & Thomas, 2009).

Home based care strategies have been found to be feasible, acceptable and cost-effective. However, care givers face substantial burdens, and are affected in a number of ways, linked to poverty, stigma and discrimination, lack of support, social exclusion, depression, emotional trauma, inadequate time for other responsibilities and sleep disturbances. Religion and hope for a cure were commonly reported coping strategies. Studies highlight the need for care and support, not just for people with mental disorders, but also for their care givers. Support can be financial, practical, or emotional (Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015; Braathen et al., 2016; Mwale, 2011; Viana et al., 2013). A study from Ghana found that many people with mental disorders in the communities were beaten, chained and had food withheld in their homes and in treatment centres in the community. This kind of response to mental disorders was embedded in spiritual and moral perspectives, and as such was accepted locally. Care for people with mental disorders was primarily provided by families and by traditional healers, with little support from health services, which were inaccessible and perceived to be ineffective (Read, Adiibokah, & Nyame, 2009).

Many ethical principles for care are universal, but some factors are subject to the influence of cultural and economic realities. This is true for some aspects of the African context, and in the planning and provision of care in this context, the communal and interdependent nature of the Ubuntu philosophy and culture should be taken into consideration (Kaseje & Mpenda, 2002). In the context of Ubuntu, it can be both inappropriate and ineffective to impose typical individual practices associated with scientific medicine. While help seeking and decision making takes on a largely individualistic approach in scientific medicine, in the context of Ubuntu people may seek help and make decisions as a group (Engelbrecht & Kasiram, 2012; Kaseje & Mpenda, 2002; Kirmayer & Swartz, 2014). However, cultural sensitivity can be problematic, and there is a fine line between respect for cultural differences and dissociation from human rights abuses (such as oppression of women, sexual minorities, racial groups, etc.) (Kirmayer & Swartz, 2014). Indeed, ethical behaviour requires interrogation of cultural practices in a context of local and global inequalities, as cultural practices can be both inclusive and exclusive in nature (Kirmayer & Swartz, 2014). In the literature, Ubuntu is generally uncritically presented in a positive and optimistic way, as a philosophy leading to inclusive practices and care. Goodley and Swartz (2016, in press) question this uncritical presentation. They do not deny the positive

aspects of Ubuntu, but acknowledge that there may be other, potentially oppressive, sides to the philosophy. For instance, in the interdependent and collective nature of Ubuntu follows obligations and responsibilities in terms of who is obliged to carry out certain care activities, or who is entitled to be part of a collective decision making process. Or, even more, who is entitled to be part of the collective that is Ubuntu (Goodley & Swartz, 2016 (in press)).

3.4.5 Medical pluralism

Medical pluralism is prevalent throughout most of the African continent, and traditional therapeutic practices remain resilient despite the introduction of scientific medicine (Akyeampong, Hill, & Kleinman, 2015). Traditional healers, such as diviners, priests and healers (including herbalists), have a long tradition in Africa, and existed long before the introduction of scientific medicine. Within these traditional systems, mental disorder is commonly ascribed to supernatural causes like witchcraft or punishment from god or ancestors. Despite this, studies of the African mind and mental disorders in Africa only arrived with colonial encounter, and psychiatry in Africa has since then been accused of taking on the perspective of scientific medicine (Akyeampong, 2015). However, since the continent's independence there has been a shift towards medical pluralism, and integration and collaboration between the different sectors of health care (Akyeampong, 2015). In line with the recommendations from the Global Mental Health movement, studies from Africa highlight the need for community based mental health care. This includes care provided at primary level, with the necessary supervision, remuneration and education for primary care workers. It also includes collaboration between scientific medicine and local, traditional healing systems (Akpalu et al., 2010; Alem, Jacobsson, & Hanlon, 2008; Hanlon, Luitel et al., 2014; Mwape et al., 2010; Ofori-Atta et al., 2010). Many people seek care from various traditional healers before they seek help from scientific medicine. This often delays help-seeking substantially, which again may compromise the treatment outcome or worsen the mental disorder. Thus, establishing robust collaboration and referral systems between scientific and traditional health care are important strategies to improve mental health service delivery (Bekele, Flisher, Alem, & Baheretebeb, 2009; Nsereko et al., 2011), but collaboration faces many challenges. Challenges include lack of respect, knowledge and understanding between the two sectors, leading to an overall scepticism towards the other sector (Ae-Ngibise et al., 2010).

In addition, self-help organisations and programmes have been found to be helpful for the recovery of mental disorder in an African context. Self-determination and self-representation, both in own treatment and recovery and in society and life in general, has been highlighted as important aspects of these programmes (Kleintjes, Lund, & Swartz, 2013b). A Kenyan study demonstrated the benefits of integrating mental health and poverty alleviation programmes

(Lund, Waruguru et al., 2013). Similarly, a study from Ghana found that measures taken to protect employment and social status for people with mental disorders were strongly associated with improved mental health (Boyce et al., 2009). Another study from Ghana found associations between socioeconomic status, adverse life events and mental disorders (Dzator, 2013). A study from Zambia found associations between food insecurity and poor mental health (Cole & Tembo, 2011). Also, religion has been found (in Ghana) to be an important factor in how people view and manage mental disorders (Osafo, Knizek, Akotia, & Hjelmeland, 2013). There is an extensive research base on the link between HIV/ AIDS and mental disorder in Africa in general and South Africa in particular, but this is outside the scope of this dissertation. In essence, studies highlight benefits of integrating mental health into HIV/AIDS prevention, treatment and care programmes (See for instance: Boyles & Joska, 2009; Collins, Holman, Freeman, & Patel, 2006; Collins, Mestry, Wainberg, Nzama, & Lindegger, 2006).

3.5 Care in a South African context

South Africa has signed many declarations ensuring right to health care for the population, but this is far from being achieved for the vulnerable population of people with psychosocial disabilities (Andersson et al., 2013). While South Africa has seen a rapid growth in the country's mental health care infrastructure since World War I (Akyeampong, 2015), during the apartheid era in South Africa a vast majority of the population, especially those living in rural and remote areas, were deprived of public health care. In these areas people were serviced primarily by traditional healers, missionary hospitals or used over-the-counter medication (WHO, 1983). In South Africa today mental disorders are less likely to be treated than physical disorders, but mental disorders are more disabling. There is a need to scale-up existing services, and to ensure that interventions are locally adapted to the South African context (Sorsdahl, Stein, & Lund, 2012).

3.5.1 Mental health policy

The South African Mental Health Care Act was adopted in 2002 (Department of Justice, 2002). In the Act mental health is described as a public health and human rights issue. As a tool to implement the Act, in 2013 South Africa adopted the Mental Health Policy Framework and Strategic Plan 2013-2020 (Department of Health, 2013), which, in line with WHO Mental Health Action Plan (WHO, 2013b), advocates for task sharing and integration of mental health into primary health care (Marais & Petersen, 2015; Schierenbeck, Johansson, Andersson, & van Rooyen, 2013). While these are all steps in the right direction towards realising the human rights of people with mental disorders, and some improvements have been made, there are still major challenges and service gaps, particularly in rural areas. Identified challenges include low priority for mental health issues, lack of funding, low priority for integrated care, lack of

capacity to develop and implement mental health care plans at provincial and district level, lack of training in mental health care for health personnel, high staff turnover and infrastructural constraints (Marais & Petersen, 2015; Petersen, Lund, Bhana, & Flisher, 2012). Despite broad agreement that people with psychosocial disabilities should be involved with mental health policy and program development, they are rarely consulted. Barriers for their involvement include stigma and lack of awareness among policy makers, poverty, poor recovery rates for mental disorders and lack of support (Kleintjes et al., 2013a).

The South African Traditional Health Practitioners Act (Republic of South Africa, 2008) is concerned with traditional medicine and practices using African techniques and principles. The act aims to regulate traditional physical and mental health care services through registration, training and control, but the practices remain largely unregulated (Peltzer, 2009).

3.5.2 Scientific health care

Historically in South Africa people with severe mental disorders were cared for in psychiatric institutions, isolated from their families and communities. While it is generally agreed that deinstitutionalisation of mental health services is a good idea, it requires development of the primary health care system and community based services to provide care for people with mental disorders. In practice in South Africa deinstitutionalization has meant that the responsibility of care for people with mental disorders has been moved from psychiatric hospitals to communities and families, while the primary health care system and community based care systems remain unable to provide appropriate care. In contexts where Ubuntu is the core life philosophy, embracing its values is an essential component in care and treatment of individuals, families and communities living with mental disorder (Engelbrecht & Kasiram, 2012).

Despite the recognition of mental health as a public health issue in South Africa, public mental health services are still under-resourced throughout the country. Mental health policy and legislation advocate for more community based mental health services, and the necessary structures for implementation have been put in place at national and provincial level. But the distribution of mental health services in South Africa remains unequal, and in many provinces there are still large unmet needs for mental health services. Eastern Cape is one of the most under resourced provinces (Lund, Kleintjes, Kakuma, Flisher, & the MHaPP Research Programme Consortium, 2010). It has been estimated that task-shifting is a cost effective strategy to close the current gap between need for mental health services and the availability of mental health services (Petersen, Lund et al., 2012).

A systematic review on lay counsellor services in South Africa found that services provided by lay counsellors contribute to improved treatment outcomes for patients with mental disorders and improved treatment adherence for patients with chronic conditions. Challenges include poor role definition, supervision and logistical support, and lack of or inconsistent remuneration and training (Petersen, Fairall, Egbe, & Bhana, 2014). Key challenges to mental health care in South Africa is training and supervision of staff at primary care level in both diagnosis and treatment of mental disorders. Another challenge is development and implementation of community based interventions for mental disorders. At primary care level a major challenge is lack of resources for mental health services at district and regional hospitals. At tertiary level there is a lack of continuity of care with primary and secondary levels, resulting in poor treatment outcomes (Lund et al., 2012).

A study of perceived barriers to mental health care by mental health care stakeholders (health professionals and public administration) was carried out in semi-urban and rural areas of the Eastern Cape Province. Identified barriers were lack of trained health personnel, lack of treatment facilities, lack of organisational capacity, lack of community services, lack of transport, lack of information, stigmatisation due to perception of psychosocial disability in society, and traditional beliefs in the community and among health providers (Schierenbeck et al., 2013).

3.5.3 Traditional healing

The traditional health practitioners included in the South African Traditional Health Practitioners Act (Republic of South Africa, 2008) are herbalists, diviners, traditional surgeons and traditional birth attendants. Spiritual and faith healers are not included, despite the fact they are as prevalent as, if not more than, the traditional health practitioners included in the Act. In South Africa, traditional healing is unregulated, lacking approved diagnostic and therapeutic methods, which allows for fraudulent practitioners (Peltzer, 2009). Adding to this, the knowledge is passed on orally, and as such there is scarce documentation and empirical evidence from the field (Cumes, 2013; Peltzer, 2009). Historically traditional healing has been the backbone of African communities, and it remains influential today, especially in rural areas of Southern Africa (Cumes, 2013). Population-based surveys from South Africa, however, indicated a decline in the use of traditional health practitioners between 1995 and 2007, but they remain important in health service delivery for a variety of health conditions, including mental disorders (Peltzer, 2009).

At the heart of Xhosa traditional healing is ancestor reverence, which is described as a worldview, not a religious system, and can thus coexist with religious beliefs. Traditional healers have historically been seen as unskilled “witchdoctors”, but many have received

several years of training and preparation to achieve ancestral approval to act as traditional healers. At the core of ancestor reverence is the belief that when a person dies, something of the person remains. Through the ritual of a funeral the transition to ancestorhood takes place. As such it is crucial to respect people even after their death, and the deceased play a crucial role in the lives of people with this worldview (Berg, 2003). Deceased ancestors act as protectors, guides and mentors to the living, and are important factors in maintaining good mental and physical health. Ancestors and their influence are kept alive through rituals and ceremonies performed by the living. Ancestors may manifest through dreams, bodily sensations or even illness. People's experiences with ancestors and their influence has been compared to Western psychoanalytical notions of the unconscious mind, and the importance of listening to messages from the unconscious to maintain good physical and mental health. People are linked to their ancestors through the clan they belong to, and the link is re-established through life-cycle rituals and ceremonies. The link can be broken if ancestors are disrespected, and if this happens their guidance and protection disappears, and individuals can be exposed to powers of witchcraft, which may manifest as mental of physical illness (Berg, 2003; Bührmann, 1982). If this happens the individual must perform rituals to re-establish the link with his/her ancestors. There are three types of ritual: life-cycle rituals (birth, initiation, marriage and death); thanks-giving rituals to thank ancestors for assisting with successful completion of a task; and illness rituals to ask for ancestors' assistance in curing illness. Consultation with traditional healers is never done alone, but the patient is accompanied by family and/or community members in the consultation and in the subsequent treatment rituals. The individual is not seen as isolated, but part of a larger group, and involvement of the group is essential for healing. Dreams are commonly seen as messages from the ancestors. Through dreams ancestors can provide directions for diagnoses or treatment for physical or mental illness. Through traditional rituals and with the help of traditional healers (links to ancestors) people receive help to dream, share the dream and find meaning in the dream. Disconnectedness from people around and from ancestors can be detrimental to mental health in collective cultures. The traditional healer is trained by ancestor, and acts as a link between ancestors and the living (Berg, 2003). A traditional healer is referred to as *"Igqira"*, commonly described as a "witchdoctor" by Western/White people (Cheetham & Cheetham, 1976).

It has been argued that African traditional belief systems and rituals can have a positive effect on mental health. It is essential that African worldviews are considered and respected in increasingly Westernised African societies, such as in South Africa (Berg, 2003). In traditional medicine, mental disorders have primarily been treated with community oriented therapy, unless the patient behaves in a violent and uncontrollable manner, in which case they can be

referred to public health services, such as psychiatric hospitals (Cheetham & Cheetham, 1976). A study of amaXhosa traditional healers in the treatment of patients with psychosis found that the healers identified symptoms in the patients consistent with symptoms of psychosis found in the DSM-IV manual. Explanatory models applied by the healers for these symptoms were primarily supernatural, linked to witchcraft, spirit possession and angered ancestors. Genetic predisposition was also mentioned as an explanation for the symptoms. In treating these patients, the healers used various cleansing rituals of washing, steaming, induced vomiting, singing and dancing. These are essential to cleanse the patients, their families and their homes of evil spirits (Mzimkulu & Simbayi, 2006). A study of explanatory models for mental disorders (as defined by DSM-IV) among South African traditional healers (diviners and herbalists) found that mental disorders with psychotic symptoms were commonly seen as illnesses, whereas mental disorders with no psychotic symptoms were not conceptualised as illnesses. The non-psychotic disorders commonly display less behavioural changes, and are conceptualised as stress-related or a result of "thinking too much", and as such are often seen as requiring no treatment, as the symptoms are considered to be normal reactions, which are sometimes physical, and thus attributed to physical illnesses such has hypertension or HIV. The healers did not believe that there was treatment available or necessary for these reactions, but rather felt that that these people could be assisted with a job or with money. Mental disorders with psychotic symptoms, on the other hand, commonly have associated behavioural changes, and the healers believe these disorders require treatment. The causes described for mental disorders with psychotic symptoms were witchcraft, possession by evil spirits, substance abuse, life stressors and *ukuthwasa* (the calling to become a healer). In the treatment of psychotic disorders, the healers reported using traditional herbs, and sometimes "modern ingredients" such as methylated spirits, which warrants some cause for concern and further exploration. The authors express concern of the low level of mental health literacy among the traditional healers, which can result in mistreatment or lack of referral to and collaboration with mental health practitioners from scientific medicine. Traditional healers have proven to play an important role in treatment adherence and prevention for illnesses such as HIV, and could be essential in mental health promotion, prevention and treatment adherence, and in the integration of people with mental disorders into the community. The effectiveness of traditional healers in mental health prevention, promotion, diagnosis and treatment is unknown, and more research is needed (Sorsdahl et al., 2010). Studies from South Africa have found that 9-15% report seeking help from traditional healers for mental disorders (Andersson et al., 2013; Sorsdahl et al., 2009).

3.5.4 Family care

A recent study from South Africa found a strong connection between lower quality family relations and unmet needs among people with mental disorders. This suggests that good family relations are crucial in meeting the care needs of people with psychosocial disabilities (Tomita et al., 2016). And indeed, global service reforms for mental health, including a shift towards integration into primary health care and more community and family based care, has been advocated for over the past decade. The implementation of these reforms has been challenging, placing additional burdens on families caring for a member with mental disorder, and thus impacting on their ability to provide care. A study from South Africa exploring impacts of household caring for a family member with mental disorder found a high household burden related to service provision, but the burden was not primarily related to caring for the household member with the mental disorder. The majority of the burden was related to seeking care from health clinics with poor clinic organisation, which was aggravated by factors such as lack of water and electricity to the household. Caregiving was made difficult when the other family members had to spend time they could have used for care giving on finding money for and sources of electricity and water, and in seeking care from a poorly organised health system. These competing demands of the care givers compromised their ability to provide care, and thus impacts on the family member with mental disorder, which again impacts on the mental health of the care givers, and further impacts on their ability to provide care. Integration of mental health services into the primary health care system often comes with managerial and logistical challenges for service delivery, especially in under-resourced and underdeveloped contexts. This places increased care burdens on households (Breen et al., 2007). Other research from South Africa also suggests that families of people with psychosocial disabilities are burdened by the care load and stigma related to the mental disorder. Adding to this, they receive very little support from scientific medicine, and are rarely included in the treatment process (Molefi, 2008). A study of psychosocial disability among isiXhosa-speaking people living in peri-urban suburbs of Cape Town found that households with family members with psychosocial disabilities face substantial consequences related to the psychosocial disability. In a context of poverty, the added burden of psychosocial disability can be detrimental to the household. The survival of a household is dependent on the contributions of all members of the household as a "collective income generating unit". If one or more household member is prevented from contributing to this unit because of psychosocial disability, or because of care obligations related to the psychosocial disability, the whole household suffers. Consequences of psychosocial disability may require a reorganisation of the whole household. Furthermore, the outside-the-norm behaviour of the person with psychosocial disability often place stigma and consequent cultural sanctions on the individual and his/her family/household, which in turn

may have economic implications. Also, the behaviour often affects the interpersonal climate in the household negatively. Relationships both within and outside the household may be challenged by this behaviour (Duncan et al., 2011a). However, in the context of severe poverty, deprivation, HIV, crime, conflict, alcoholism and more, it is difficult to single out consequences specifically related to psychosocial disability, as all of these experiences are tied together. One factor that aides with coping are social grants, in this case the disability grants (Duncan, Swartz, & Kathard, 2011b).

There is a lack of research in this particular area. Policies must be adapted to relevant contexts and cultures, and not just follow international trends and priorities. There is a need for contextual and cultural evidence to inform policy and service development (Breen et al., 2007). Breen and colleagues (2007a) highlight "the importance of taking the time to develop a more nuanced sense of how poor families coping with mental disorder and disability live" (Breen et al., 2007, p. 333).

3.5.5 Medical pluralism

Many South Africans utilise scientific and traditional health services simultaneously, as it is commonly believed that scientific medicine can diagnose and treat the pathology, while traditional healers can find and deal with the cause of the illness, often related to harmful spirits. Thus, the two systems can coexist successfully, but there are often tensions between the two, and collaboration can be challenging (Peltzer, 2009). Most of the Black population in South Africa use both traditional healing and scientific medicine (offered through the public health care system) in the treatment and care of mental disorders. Despite this, collaborations between the two sectors of care has been limited. These service users commonly hold illness beliefs that resonate more with traditional systems of healing than with scientific medicine. The shift back and forth between these two care systems often reduces treatment adherence. Traditional healers have expressed frustration that scientific health care practitioners do not appreciate and respect traditional healing and care. They are, however, open to collaboration with and training by scientific health practitioners. Scientific health practitioners, on the other hand are more reluctant towards such collaboration. However, a collaboration is widely argued for to provide holistic care to patients who seek care from both health care systems simultaneously (Campbell-Hall et al., 2010; Mzimkulu & Simbayi, 2006; Ross, 2008). A population-level survey of common mental disorders (CMD) in South Africa found that a minority of people with a diagnosable (DSM-IV) CMD had sought treatment from scientific (29%) or alternative (20%) practitioners. Only 9% reported having consulted a traditional healer, and 11% had consulted a religious or spiritual healer. Among those who had consulted a traditional healer, the majority were Black, older-aged, unemployed and had lower education,

and they most commonly had symptoms of anxiety or substance use disorder. Among the Black respondents, almost half (49%) had consulted a religious or spiritual healer, and 21% had consulted a traditional healer (Sorsdahl et al., 2009).

A study from South Africa found that traditional healers report having the ability to treat and cure people who present with obvious symptoms of mental disorder, which they understand as “abnormal behaviour”. The healers do occasionally refer these patients to scientific Health care, but primarily as a last or temporary resort if patients show signs of uncontrollable behaviour of violence and aggression. They believe that scientific medicine can be useful in making patients calm and more susceptible to traditional medicine, but not successful in curing mental disorder alone. The healers report that they feel they are treated with a lack of respect by scientific health professionals. Traditional healers should be trained in recognising a broader range of mental disorder, and better communication and collaboration between scientific and traditional systems of care and healing is called for (Sorsdahl, Stein, & Flisher, 2010).

In the context of communities like Madwaleni, psychiatry and traditional healing are competing but co-existing health systems, with subsequent tensions. In the context of psychiatry, psychologists and psychiatrists are mostly White, not sharing the culture of their patients. Nurses, on the other hand, are often Black, of the same culture as their patients, and seen as being "one of us" by patients. But while many nurses are from the same cultural and geographical background as their patients, their medical training is scientific medicine, and they are also seen as being “one of us” by the psychiatrists and psychologists. As such, they hold a unique position as the link between the traditional belief system of the patients, and scientific medicine. Studies have shown that these nurses often subscribe to a pluralistic understanding of health, drawing on principles both from the field of scientific medicine, where they have received medical training, and from the “traditional” health system they have been born, raised and live in. But where there is a conflict between the two health systems they tend to give priority to scientific medicine, and as such, traditional medicine and healing often ends up being the subordinate system in contexts where there is medical pluralism (Kahn & Kelly, 2001).

Community participation has been advocated for as an important tool towards scaling up mental health services in a South African context; promoting mobilisation of resources, ensuring that services are culturally and contextually appropriate and that care receivers are empowered. Community participation can be done through involvement in community forums to strengthen awareness and collaboration of mental health issues among key stakeholders, such as policy makers, and scientific medicine and traditional health providers. Community

members can also be involved in the development and delivery of mental health interventions, which has proven particularly useful to ensure the cultural and contextual relevance of interventions. Community participation also provides support, coping and empowerment for the community members who participate, which also emphasises the importance of peer-groups and support to improve mental health among poor community members. The community participants are mostly economically marginalised, rural, African (Black) women. These women are commonly discriminated against because of their race, gender and economic status, and thus a challenge for community participation is that those involved have limited power to influence substantial structural or cultural change (Petersen, Baillie, & Bhana, 2012). Community health workers have proven to be important recourses for community involvement towards promotion and treatment of mental health issues, but because they are volunteers with no formal education they often experience lack of respect from other community members and service providers (Petersen, Baillie, et al., 2012).

3.5.6 Integrated health and social services for mental health

Studies from South Africa have found support for a direct link between mental disorder and poverty and other social determinants. The link could be through reduction in earnings, increased costs and loss of income due to impairments, lack of participation and stigma experienced by people with mental disorders. Another explanation could be that people in lower income groups have increased risk for acquiring a mental disorder. Regardless, there is support for the argument that in addressing poverty related issues, mental health issues should also be included (Lund, Myer, Stein, Williams, & Flisher, 2013; Slopen et al., 2010; Sorsdahl et al., 2011).

Studies from across the world, including South Africa, have found high levels of comorbidity between chronic illnesses such as HIV and hypertension and mental disorders (See for instance: Collins, Holman, et al., 2006; Grimsrud, Stein, Seedat, Williams, & Myer, 2009; Petersen, et al., 2016), supporting the argument for increased integration of these health services. An integrated approach, however, is complex, and requires integration and support at organisational, facility and community levels, in addition to task shifting and task sharing. In this context it is important to be mindful of the extra burdens this may place on an already pressed South African public health system (Petersen, et al., 2016). Adding to this, Brooke-Sumner and colleagues (2016) advocate for a broader communication and collaboration between different government sectors, such as Health and Social Development and non-government organisations (NGOs) in the provision of psychosocial rehabilitation in South Africa (Brooke-Sumner, Lund, & Petersen, 2016).

3.5.7 Help-seeking

A study from South Africa found low levels of mental health service use, resulting in a large burden of untreated mental disorders in the population. About one in four people identified with severe mental disorder reported having sought some form of treatment over a period of 12 months. Many had sought help in the general health sector, and not in the mental health sector. Black respondents were the least likely to have sought help from the mental health sector. The study found provincial variations, with the highest levels of help-seeking in Western Cape Province, and substantially lower levels in, for instance, Eastern Cape Province. Women were more likely than men to seek treatment (Seedat et al., 2009). A number of barriers for the utilisation of mental health services in South Africa have been identified. These include mental health stigma and knowledge, affordability of services, impersonal services, lack of trust in service providers and lack of culturally sensitive services and providers. Racial and cultural differences between users and providers have also been highlighted as barriers to service utilisation (Ruane, 2010).

Studies have revealed low levels of health literacy among people with epilepsy and their carers in South Africa. An observational study in a clinic in Cape Town found that epilepsy patients received the health care they are entitled to, but they saw many missed opportunities to improve health literacy among these patients. They also saw factors in the interaction between epilepsy patients and health providers that could contribute to poor understanding and management of epilepsy (Keikelame & Swartz, 2013b). Low mental health literacy has also been found among South African patients with schizophrenia and their carers. This is attributed to poor information disseminated in a top-down approach by health providers. A more participative approach is advocated for, involving and consulting the patients and their carers (Motlana, Sokudela, Moraka, Roos, & Snyman, 2004).

A study on depression from an urban area in the Eastern Cape province of South Africa found higher rates of depression among adults in this population compared to the findings of studies from other parts of South Africa (Andersson et al., 2013). More than a third of the study population reported having had symptoms of depression sometime during their life. The authors suggest that the high levels of depression could be linked to high poverty levels, economic distress and social unrest, low levels of employment, and trauma due to high levels of crime, violence and HIV. More than half of those who had experienced depression had not sought health care. Major barriers to accessing health care was reported to be lack of availability (long waiting times) and affordability (cost) of the health care, low mental health literacy among the informants and stigma. Also lack of professionalism and competence among health workers was said to have potential for improvement, although many informants

who had used health services were satisfied. Many informants also reported lack of trust that health workers would keep their problem confidential as a barrier to seeking help. Social support from family and friends and willingness to disclose the problem were factors that increased the likelihood of help-seeking. Also having a comorbid illness increased help-seeking, which could be because they were already involved with the health system. Overall, people expressed a wish to cope with their mental illness on their own without seeking help, and many also believed the problem would pass without intervention (Andersson et al., 2013). However, other South African studies have found even lower levels of help-seeking (Seedat et al., 2009).

A study from South Africa found that stigma and discrimination against people with psychosocial disabilities are major barriers to help seeking and recovery. People with psychosocial disabilities reported being stigmatised by family members, friends, community members, employers and health care providers. Stigma was found to be caused by lack of knowledge and misconceptions about psychosocial disability, which often leads to delays in help-seeking. Knowledge and awareness about psychosocial disabilities should be raised through media campaigns and counselling of families, care givers and service users (Egbe et al., 2014). A number of innovative strategies have been developed and applied throughout South Africa to address stigma and increase awareness about mental health. However, the impact of these strategies is unknown, as they have not formally been evaluated. It is essential that such strategies are culturally and contextually appropriate, and involvement of the “consumers” (the people exposed to stigma) has said to be the key ingredient for success. Strategies must be based on contextually and culturally relevant evidence on mental health stigma and awareness, and use appropriate methods to reach the target population (Kakuma et al., 2010).

3.6 Concluding statement

Chapter Three has given an overview of the evidence on care for people with psychosocial disabilities in low-income contexts in general and in Africa and South Africa more particularly. In summary the evidence shows that in LMICs, including South Africa, the gap between the need for mental health services and available services is critical. Reasons for this have been said to be lack of priority at policy level, lack of equipment, personnel, and medication, in addition to low mental health literacy. The result is that the majority of people with psychosocial disabilities are not diagnosed or treated. In order to close the gap between need and provision, there is a call for more community based mental health services, for task-shifting and a move towards recognising medical pluralism.

The identified gaps in knowledge in the field of Global Mental Health are too extensive to be covered in this dissertation, and I have thus narrowed the scope to exploring structures of care for people with psychosocial disabilities in Madwaleni, South Africa. In the next chapter I will describe the methodology and data collection techniques I have utilised to explore these phenomena.

Chapter Four: Methodology

4.1 Chapter outline

This chapter will describe and discuss the rationale behind the chosen study design. I will address critical issues related to data collection techniques, interpretation, reflexivity and data analysis, in addition to a description of the informants, sampling and data collection techniques. Ethical issues that have been important to consider in this study, and how they have been dealt with, are described below.

This study utilises data from two research projects, as described in Chapter 1.3. The primary data of this project, however, the case study data, is collected exclusively for this PhD. Data from the two former projects is used as contextual data to the case studies, in addition to contextual data collected only for the purpose of this dissertation. The methodology and data collection techniques for collection of both the contextual data and case study data are described below.

4.2 Study design

4.2.1 Qualitative study design

> If the goal is not to generalise to a population but to obtain insights into a phenomenon, individuals, or events, as will typically be the case in qualitative research, then the researcher purposefully selects individuals, groups, and settings that maximise understanding of the phenomenon. (Onwuegbuzie & Leech, 2007, p. 111)

As the above quote states, choice of study design depends on what one wishes to accomplish with a study. When one wishes to study complex issues, such as what something means to people or why they act in certain ways, a qualitative research design is deemed suitable, while if the aim is to study how many, or other measurable factors, a quantitative survey design would be more appropriate (Holloway & Biley, 2011; Hollway & Jefferson, 2013; Onwuegbuzie & Leech, 2007; Willig, 2013). To impose an unsuitable research design on a study may cause loss of credibility for the study, leading to results of poor validity. The choice of a study design hence depends on the questions one wishes to answer, and hence at the heart of any research design are the research questions and the objectives for the research (Morse & Richards, 2002; Stake, 2006; Willig, 2013; Yin, 2013). As outlined in Chapter 1.2, the research questions for this study are of an exploratory nature, linked to meaning rather than measurement, and therefore a qualitative research design has been chosen.

> . . .qualitative inquiry is. . .the most humanistic and person-centered way of discovering and uncovering thoughts and action of human beings. (Holloway and Biley, 2011, p. 975)

While qualitative studies are not primarily about generalising the results to a broader population, all studies aim to test various hypotheses against available research evidence. The informants in qualitative studies are therefore not first and foremost of interest to themselves, but rather to their importance in verifying, explaining or exploring a broader theoretical hypothesis (Hollway & Jefferson, 2013). Onwuegbuzie and Leech (2007) argue that if generalisation is not the goal, which it is usually not in qualitative research, theory should only be outlined in terms of the particular informants, setting, context, location, time, event, incident, activity, experience and/or process. One can only generalise as long as the generalisations are made localised.

The aim of this study was to explore practices, views, knowledge and experiences related to care for people with psychosocial disabilities living in a rural South African context. To do this, I follow Morse & Richards' (2002) argument that "you need methods that will allow you to discover and do justice to their perceptions and the complexity of their interpretations" (Morse & Richards, 2002, p. 28), and qualitative methods can do this. Furthermore, "you need methods for discovery of central themes and analysis of core concerns" (Morse & Richards, 2002, p. 28). This study aimed to explore cultural contexts and phenomena from the perspectives of the members of the cultural groups explored (emic perspective) (Morse & Richards, 2002).

Within a qualitative research design there are numerous methodologies to choose from. This project uses a case study methodology, a suitable research method when the research questions require extensive, in-depth descriptions of social phenomena (Stake, 2006; Yin, 2013).

In qualitative research, initial methodological decisions and plans must be made, but it is crucial to revisit and revise these decisions throughout the fieldwork and adapt the methodology to the context and the real events of the data collection (Onwuegbuzie & Leech, 2007).

This study fits within a relativist approach; acknowledging multiple realities and multiple meanings about the same phenomenon (Yin, 2013). The findings were dependent not just on the informants, but also on the observer, listener, interpreter, communicator, and so on. The relativist approach is opposite to the realist approach, assuming the existence of a single reality, independent of the observer (Yin, 2013).

4.2.2 Two data collection parts

This study is divided into two linked, but methodologically different, parts, namely the contextual part and the case study part. The overarching methodological principles are the same; they are both anchored within a qualitative, explorative research design. While the overall objective is the same for the two parts, the specific research questions differ, as do the data collection and analysis techniques. The reasoning for these two approaches is that case studies are investigations of contemporary phenomena in real-world contexts, and boundaries between the phenomena and its context are blurred. Therefore, Yin (2013) argues that "other methodological characteristics become relevant as the features of a case study" (Yin, 2013, p. 17). The contextual study addresses these "features", and the research questions are therefore towards the context, rather than towards individuals, which it is for the case studies. Most of the data collection for the contextual part was carried out prior to the case studies.

1. Contextual study

The overall goal of the contextual study was to identify and explore people, institutions and places that offer some kind of care for people with psychosocial disabilities in Madwaleni. The goal was to provide as detailed as possible a picture of these care structures and how they operate in Madwaleni. Data were collected to develop a contextual and cultural understanding of the setting in which the case studies function. Furthermore, it was crucial to get a good picture of the Madwaleni context (lay-out, terrain, how people live and so on) and certain cultural aspects (common beliefs and practices), particularly those related to psychosocial disability. The contextual study used a number of different qualitative data collection techniques, which are described in more detail in Chapter 4.3 below. The majority of the data collected for the contextual study was collected as part of the EquitAble study and the study on access to health services for people with disabilities in South Africa and Malawi (see chapter 1.3). Some additional interviews were conducted solely for the purpose of this dissertation, with a primary emphasis on mental health services and structures of care for people with psychosocial disabilities.

2. Case studies

The overall goal of the case studies was to explore decisions related to seeking and giving care; why they were taken, how they were implemented and with what result (Yin, 2013). There are six case studies of people with psychosocial disabilities from Madwaleni. A case study is the study of an integrated system, with interactions within and across cases. Case studies are suited to study the experience of real people in real situations. A case is dynamic, operating in real time. While it has stages of life, and only the "now" can be observed, history and future

are also part of the bigger picture (Stake, 2006, p. 3). In multiple case studies, like this study, the cases are similar or have some commonalities, and they are studied alone, as well as in relation to each other and in relation to the overall study phenomenon (Stake, 2006). In this particular study the cases are people with psychosocial disabilities, and the overall study phenomenon is that of care for this group of people. Each case is an in-depth description and exploration of a person from the perspective of the individual, and/or from their family members.

All the case study interviews were carried out solely for the purpose of this dissertation.

4.2.3 Case study methodology

A case study design has been chosen as the methodology for this study. Case study is a common research method in many social sciences such as psychology, sociology, political science, anthropology, social work, and so on (Yin, 2013). This study design is particularly useful when one needs in-depth information about an issue, event or phenomenon in its natural real-life context. It is well suited for exploring attitudes to and experiences of this phenomenon, which could for example be a patient's experience of care (Crowe et al., 2011). The design is particularly useful to illuminate processes of decision-making; why decisions were taken, how they were implemented and with what result (Yin, 2013). Case studies are useful in building theory, as they aim towards particularisation rather than generalisation (Stake, 2006). Case studies typically investigate contemporary phenomena (as opposed to historical) in real-world contexts, where the boundaries between phenomena and context are blurred (Crowe et al., 2011; Yin, 2013). But while only the "now" can be observed, history and future are also part of the bigger picture for the case (Stake, 2006). A case study does not respresent a sample, a population or universes, and hence statistical generalisations are not relevant. Case studies can be generalised only to theoretical dispositions with the aim of expanding theories, commonly referred to as analytic generalisations (Yin, 2013).

Cases should possess similar characteristics, and may be individuals, organisations, processes, programmes, neighbourhoods, institutions or events (Stake, 2006; Yin, 2013). In this particular study, the cases are individuals with psychosocial disabilities. I have used a multi-case approach, where several cases are used to examine a particular functioning or phenomenon, often referred to as a quintain (Stake, 2006), which in this study is care for people with psychosocial disability. The starting point for a multicase study is to understand the quintain. This is different in single case studies, where the case is the starting point which one is trying to understand (Stake, 2006).

In a multicase study design the researcher can spend a short or a long time with each case. The aim is to get an understanding of each case, normally one case at a time, in its real-life context (Stake, 2006). The primary data in case studies are from the cases, but data can also be collected from other sources that shed light on the quintain (Stake, 2006). Case studies commonly draw upon multiple sources of evidence for the same phenomenon/quintain, such as interviews, observations, documents, artefacts, and so on. This is referred to as triangulation (Yin, 2013).

While research questions are essential to all research, in case study investigations too much focus on these can distract the researcher from seeing new issues that emerge from the data. Too little focus, on the other hand, can leave the researcher unprepared and unable to pick up evidence that support theories, hypothesis or relationships. In case studies, as in most qualitative research, some research questions will be answered, some only partially answered, some not answered at all and some new questions may emerge (Stake, 2006).

4.3 Data collection techniques

Case study research commonly utilise multiple sources of evidence and multiple data collection techniques, collecting data on the same phenomenon. This is referred to as triangulation, which is an overall method of gaining assurance or validity. Triangulation can be a combination of data collection techniques; as stated above, it can be a combination of evidence collected by different researchers, a combination of qualitative and quantitative evidence, or several theoretical perspectives of the same data (Crowe et al., 2011; Stake, 2006; Yin, 2013). In this project, triangulation primarily refers to a combination of data collection techniques, but also, in the contextual study, a combination of researchers collecting data. Commonly used data collection techniques in qualitative studies are in-depth, semi-structured interviews and conversations (individual and groups/semi-structured and un-structured), relevant background literature, theory, diaries, films, recordings, official documents, newspaper articles, extensive field notes and photographs, in addition to non-participant through to full-participant observation (Morse & Richards, 2002; Stake, 2006; Yin, 2013). While it is important to start with a plan, one must be prepared for emerging issues that force one to change that plan (Stake, 2006; Yin, 2013). The key is that data are collected from various sources that shed light on the questions under study (Corbin & Strauss, 2008). Below I will outline the different data collection techniques utilised in this study.

4.3.1 Desk study

Before, during and after data collection a desk study was carried out on relevant research, policies, official documents, and theoretical and methodological frameworks. To

methodologically and theoretically anchor the study, a preliminary desk study was carried out prior to the data collection and analysis. In addition to this, other documents, theory and research emerged throughout data collection and analysis that were also important to include. The desk study primarily forms the literature review and methodology chapters of this dissertation, but some elements of the desk study were crucial to the results chapter describing the context of Madwaleni.

4.3.2 In-depth interviews

The primary data collection technique for both the contextual study and the case studies was qualitative interviews; in-depth and semi-structured interviews through to more informal conversations. All qualitative research interviews are like conversations, but they are not conversations between equal partners (Kvale, 1996; Yin, 2013). They are controlled by the researcher, who is the person with a purpose and goal with the conversation. The researcher introduces the topic and guides the conversation (Kvale, 1996). Rather than a rigid set of questions, in-depth interviews are fluid, following the stories of the informant. 'Why-questions" are often at the heart of qualitative enquiry, but these can be difficult and unsuitable to use in an interview setting, as they can create defensiveness in the informant. Therefore, other open-ended questions, such as "what-questions" may be better suited. The researcher has to balance between his or her desire to answer the overall research questions, and asking friendly, curious and non-threatening questions in the interview (Yin, 2013).

In the contextual study I carried out some group interviews, but mostly individual interviews. The informants were largely interviewed in their workplace (health providers) or in their homes (traditional authorities/community health workers). Interviews were spontaneous and unstructured in nature, flowed more like conversations, and were frequently interrupted by activities and tasks of daily life or work life of the informants.

I carried out two types of case study interviews; prolonged interviews and shorter interviews. The prolonged interviews were long, often multiple interviews with or about the same informant and in different settings. The shorter interviews were about one hour long, and only one interview with or about the same informant. The prolonged interviews were less structured, whereas the short interviews to a larger extent followed the set interview guide (Yin, 2013).

The case study interviews were all conducted by me, the PhD candidate, together with two different isiXhosa-speaking interpreters. Most of the contextual interviews were also carried out by me, but a few where done by colleagues from Stellenbosch University as part of the overall EquitAble project. Details of all the interviews carried out for this dissertation will be tabulated in the results chapters.

One of the biggest challenges with qualitative interviews as research method is the validity of the knowledge obtained for the social world in which it is found (Kvale, 1996). Validity is connected to interpretation. In qualitative studies this could be the interpretation of the interviewee of the question asked by the researcher, or it could be the researcher's interpretation of the informant's answer. To ensure validity the researcher must make sure that questions and statements are clear and easy to understand, and avoid ambiguous words and formulations. On the other hand, to ensure the validity of the informants' responses, the researcher can ask follow-up and clarifying questions, or repeat the answer and say, "is that what you are saying?" (Kvale, 1996). Furthermore, validity is ensured by posing the same question to several different sources of information; different informants, literature, policies, and so on (Corbin & Strauss, 2008; Stake, 2006; Yin, 2013). Validity will be discussed further in Chapter 4.7.

Qualitative research interviews are more than just a set of open-ended questions. There are many issues to be aware of and consider for the interviewer, such as the way in which questions are phrased and asked, the physical as well as verbal interaction between the interviewer and the interviewee, interpretation of the responses, follow-up questions, and more (Hollway & Jefferson, 2013). The interviewer has to constantly consider what in a conversation is or may be relevant for the research questions; which issues to explore more extensively, and which issues not to pursue further (Hollway & Jefferson, 2013).

Interviews can be done on the phone, in writing, or in person/face-to-face. Face-to-face interviews allow for much broader data, if the interviewer is conscious of observing the surroundings for the interview, body-language and reactions of the interviewee, and so on (Hollway & Jefferson, 2013). All the interviews in this project were done face-to-face.

Hollway and Jefferson (2013) talk about problems of trust and validity in qualitative interviews. First, they talk about what they call the "transparent self problem", the assumption that informants are "telling it like it is", that they know who they are and what makes them tick. This is not always true for human beings, and presents a problem for qualitative research interviews. Furthermore, they talk about the "transparent account problem"; referring to the assumption that informants are willing and able to share all kinds of information about themselves with the researcher who is usually a stranger. Hollway and Jefferson (2013) argue that while we in qualitative interviews take everything we hear at face value, in everyday conversations we question and challenge other people's stories and views. They argue that we need to bring more of this into the qualitative research process.

Interviewing

In a qualitative research interview the main responsibility of the interviewer is to be a good listener, while the responsibility of the informant is to be the story teller (Hollway & Jefferson, 2013; Yin, 2013). A good listener is someone who assimilates information without bias, hears the exact words, sees mood and affective components and understands the context from which the informant understands the world. S/he needs to keep his/her eyes and ears open for unexpected findings that go against what was expected to be found (Yin, 2013). A number of factors can contribute to the outcome of an interview, such as the behaviour of the interviewer (tiredness, poor concentration, and so on), question formulation (open/closed-ended, non-judgemental and leading, and so on) and power relations between interviewer and interviewee (see Chapter 4.6 on reflexivity) (Hollway & Jefferson, 2013). Successful interviewing requires awareness about the factors above, as well as a good interview technique based on theoretically, culturally and contextually based questions that are well formulated and presented. Qualitative interviews should flow like conversations, but the conversation is led by the interviewer based on his/her research agenda (Hollway & Jefferson, 2013; Kvale, 1996).

One commonly starts an interview by introducing the informant to the research and telling them about their rights. It is important to ensure that the informant is well informed about the research, so as to give a qualified informed consent to participate. However, for the sake of the interview, it is important not to introduce the topic in such a way as to lead the informant into assumptions about what the researcher expects them to answer (Hollway & Jefferson, 2013). In this study I introduced the research topic very generally, saying that I wanted to talk to them about their experiences with mental illness in the family or community. What I noticed when early on in the interview I asked them about their health ("How is your health?"), almost all the informants started talking about mental health. Similarly, in my previous research about disability (Braathen & Ingstad, 2006; Braathen & Kvam, 2008; Braathen & Loeb, 2011; Braathen et al., 2015, Braathen et al., 2016) I introduced disability as a topic, and when I asked about the informants' general health they started talking about their disabilities.

A good qualitative researcher has the ability to ask good questions, to behave appropriately, be adaptive, to listen in such a way as to encourage the informant to speak comfortably and freely, to tease out subtle meaning, to know how to avoid bias, and to have high ethical research standards. This requires both content knowledge and interviewing skills and experience, as well as a good grasp of theory and methodology (Stake, 2006; Yin, 2013). A well trained and experienced researcher is crucial in qualitative data collection; it requires an enquiring mind during data collection, not just in the planning and analysis/write-up phase. Therefore, it has been argued that it is not preferable to use research assistants to collect qualitative data (Yin, 2013).

Interview guide

In qualitative interviews it is important to start with a plan, with an anticipation of themes and situations that will arise during data collection. One must, however, be prepared for late-emerging situations and issues, and make sure not to arrive with a closed mind, but rather with an eye for what to look for (Stake, 2006, p. 30).

The interviews were led by an interview guide (see Appendix D) to ensure that similar topics were covered, while also allowing for open descriptions by the interviewees. As I became more and more familiar with the context and culture of the research site, the interview guide changed. Some questions were eliminated and some questions were added. I also found that I used the interview guide less and less as the fieldwork progressed, both because I remembered the questions better, and also because I found that the conversations were more natural and I got better information when I let the informants rather than the interview guide lead the conversations. In most of the interviews the informants stuck to the relevant topics, and I believe this was because I had introduced the study to them, so they knew what I wanted to talk about.

Interpretation

Sharing a language with an informant facilitates communication, saves time and avoids distortion of the information by interpreters. It also better enables the researcher to follow the conversation, ask follow-up questions and ask for clarifications (Munthali, 2001). In this project, however, the researcher and the informants did not always share a language. In the interviews where interpretation was needed the interviewer asked the questions in English, which were then interpreted into isiXhosa for the informants. Most of the informants replied in isiXhosa, and their responses were interpreted into English. Four different interpreters were used in the data collection for this project, two in the contextual study and two in the case study component. They were all untrained and inexperienced as interpreters. They were isiXhosa-speaking people who spoke good English. Two of them were residents of Madwaleni and two were Cape Town residents. The transcriptions were done in English by the researcher. Some of the key terms to this project were checked by two isiXhosa-speaking (with isiXhosa as their mother tongue) academics from Stellenbosch University.

While it is widely recognised that interpretation is highly skilled work, in low-income contexts, such as Madwaleni, there are few or no trained interpreters, and thus alternative arrangements had to be made (Swartz, 2014b). Using untrained interpreters, researchers have to pay special attention to potential challenges and pitfalls, to ensure that the interpretation does not reduce the quality of the data collected and to adhere to crucial ethical principles. When an interpreter is present in the interview the interpreter is bound by the same rules and principles for

confidentiality as the researcher, as outlined in the protocol and in the approval from ethical committees (Swartz, 2014b; Swartz & Rohleder, 2008). The interpreters that were used in this project were trained, guided and supervised by the researcher prior to and during data collection. They were made aware of their ethical obligations and signed a confidentiality agreement. Furthermore, it is important to discuss and be aware of what role the interpreter should have in the interview. This should be addressed in training, and should also be an ongoing awareness throughout data collection; before, during and after each interview. Using an interpreter automatically creates a triangular relationship in the interview. What was intended to be a relationship between a researcher and an informant becomes a relationship among three people, and such relationships can be difficult to manage. In triangular communication and relationships, alliances often develop between two of the three participants, and these alliances are commonly developed between the interpreter and either the informant or the researcher. Such alliances can create power struggles between the researcher and the interpreter, and this can compromise the quality of the communication and information gained in the interview (Swartz, 2014b). The interpreter should be an interpreter, and not take on the role as researcher leading the interview and asking the questions. It is crucial for the researcher and the interpreter to develop a common understanding of the role of the interpreter in the interview, as well as what should be interpreted. In qualitative research the researcher is often interested in more than just the words that are spoken, but also how things are said. The interpreter should interpret everything that is said, not just a summary of it, as close to what was explicitly said as possible. They should avoid adding their own personal interpretations and clarifications (Swartz, 2014b; Swartz & Rohleder, 2008). Clear roles and a trusting relationship between the researcher and the interpreter is essential to create an interview setting that feels safe for the informant and is conducive to talking and sharing. The role of the researcher and the interpreter should be communicated clearly to the informant, so they know what they can expect from them both and from the interview. Conversations and discussions between the researcher and interpreter in a language foreign to the informant should be avoided when the informant is present, as this can be both upsetting and intimidating (Swartz, 2014b).

Strengths and weaknesses of interpretation, and how they have been dealt with in this project, will be elaborated on in the discussion chapter.

Recording

Another issue to be considered in all qualitative interviews are the pros and cons of using a voice recorder to record the conversation. On the one hand, recording interviews allows for much more accurate and detailed notes and transcriptions, which are very useful in the analysis and publication process. On the other hand, transcription is time-consuming and some

informants feel uncomfortable being recorded, and it may therefore reduce the quality of the interview (Yin, 2013).

My experience is that when informants were comfortable with the voice recorder, this enhanced the quality of the interview substantially. This was partly because of the quality of the transcription, but also because it allowed me, as a researcher, to be more present in the interview; to listen and to engage with the informant. When informants were uncomfortable with the recorder, as was the case with several informants, I did not use it, but in these interviews most of my focus became on taking good notes, and this compromised the good dialogue between me and the informant. When I took detailed notes I felt that the conversation took place between the interpreter and the informant, rather than between me and the informant. In the case study interviews all but one were recorded and transcribed verbatim (the English translation). In the interviews for the contextual study, about half the interviews were recorded, and half of them were not.

4.3.3 Observation

Case studies take place in real-world settings and in real time, and therefore automatically allow for some direct observation. Direct observation is different from participant observation in that in the latter the researcher is a participant in the setting, not merely a passive observer. I did not do participant observation, but I was a passive observer in everyday activities through to special occasions and ceremonies in the real-world setting in which I conducted my research (Yin, 2013).

The primary form of direct observation done in this study was observation in and around the interview setting. I observed the surroundings for the interview; where it took place, what it looked like, who was present, and so on. In the case studies, most of the interviews took place inside the informant's homes, and through observation I gained valuable information about their lives. Furthermore, observation in the actual interview is a crucial part of qualitative interviews, because emotions and reactions of participants are important data. Voice is the primary source of data, but behaviour is also crucial, such as silences, emotional reactions and hesitations (Holloway & Biley, 2011). In addition to observation in the interviews, I observed various community activities (market, shops, walking around in the community), health care activities, religious activities (church ceremonies) and traditional activities (funerals).

My observations were reflected in extensive field notes, and notes linked to each transcribed interview.

4.3.4 Pictures

Pictures can be used as a source of data in qualitative research. Pictures are particularly useful to convey things that are difficult to communicate in writing to outside observers or readers (Russell & Diaz, 2013; Yin, 2013). In this dissertation I have used pictures to assist the reader in getting a better idea of the context, but I have chosen not to use identifiable pictures of the informants. This is to ensure the anonymity of the informants in this study. To take pictures of humans, one needs to get permission, and it raises a number of ethical questions related to confidentiality and informed consent (Yin, 2013). However, research from South Africa has shown that most people are in fact happy to be photographed and for their pictures to be used in dissemination of results (Mji, Schneider, Vergunst, & Swartz, 2013). In this particular project, however, I felt that the informants' anonymity was more important than what extra data I may or may not have gained from the use of their pictures.

A conscious choice has been made not to keep the study site anonymous. This decision was based on discussions with staff and management at Madwaleni District Hospital who expressed a wish for the hospital and the catchment area to remain known in publications based on research data from that area. I have therefore used pictures from Madwaleni throughout the results section, as illustrations of the Madwaleni context.

4.4 Informants and sampling

> For qualitative fieldwork, we will usually draw a purposive sample of cases, a sample tailored to our study; this will build in variety and create opportunities for intensive study. (Stake, 2006, p. 24)

In qualitative research, sampling is about finding a few relevant cases that shed light or give insight and meaning to processes or practices happening in a particular context (Onwuegbuzie & Leech, 2007). In this particular project informants were chosen to study processes and practices related to caring for people with psychosocial disability in Madwaleni, South Africa. Sampling refers not just to the number and type of informants, but also to the amount of data collected; how much time spent, number of contacts, and how many questions asked of the informants. A number of factors come into play in sampling, first and foremost one must consider what is the most suitable approach to answer the research questions, but other factors, such as available time and resources, are also important (Onwuegbuzie & Leech, 2007).

Qualitative research sampling can be done using many different approaches; it is common to use several sampling techniques concurrently, and for sampling strategies to change dynamically with the development of the research (Onwuegbuzie & Leech, 2007). Below I will

describe the sampling techniques used in the different components of this study. In many qualitative studies where data are commonly collected and analysed concurrently, it is common to start with a process of convenience sampling, aiming to obtain an overview of the research field and the study area (Morse, 2007). Convenience sampling was utilised in the early stages of data collection for the contextual parts of this study. In convenience sampling one selects informants that are available and willing to participate at the time (Onwuegbuzie & Leech, 2007). Following the convenience sampling, I used a combination of purposeful sampling and theoretical sampling. In purposeful sampling one selects a case or informant because it illustrates certain characteristics one may find interesting, because it fits the parameters of the population one is studying, or because they are information-rich (Morse, 2007; Onwuegbuzie & Leech, 2007; Silverman, 2013). Theoretical sampling is closely related to purposeful sampling, but the sampling becomes theoretical when the purposeful sampling is theoretically defined in relation to the research questions and the study's theoretical position and with the aim to develop or expand theory (Morse, 2007; Onwuegbuzie & Leech, 2007; Silverman, 2013).

While informants were purposively sampled to fit into a few categories, within the categories a principle of maximum variation sampling was applied, attempting to include people of different (adult) age groups, gender, type of psychosocial disability, education levels, users of different types of health services, type of health provider, and so on. This was done to gain multiple perspectives on the same phenomena (Onwuegbuzie & Leech, 2007). Once data collection had started, informants were identified through a snow-ball method, where people who had already participated as informants were asked to help recruit new informants (Onwuegbuzie & Leech, 2007). Furthermore, with each informant I, the interviewer, considered the relevance of that particular informant to this study, and based on information provided in each interview I considered which other people and types of informants I should interview (Onwuegbuzie & Leech, 2007).

In multiple-case studies, criteria for selecting cases are their relevance to the topic under study (quintain), diversity across contexts and opportunities to learn from them about complexities and context (Stake, 2006, p. 23). It is important to choose cases that will most likely shed additional light on one's research questions (Yin, 2013), but a maximum of six and minimum of four cases has been suggested (Stake, 2006). I ended up with six case study informants with various degrees and types of psychosocial disabilities. They were all isiXhosa-speaking from Madwaleni, above 18 years, but ranging in age from youth to elderly, and including both male and female cases.

Sampling of informants for the contextual study followed similar sampling techniques as for the case study informants. A principle of maximum variation was applied aiming to include different health professionals, including relevant health professionals from different levels of both the professional and folk sector, as well lay-health workers, administrative personnel, volunteers, etc. The providers were identified through hospitals/clinics/health facilities, or through a snow-balling method.

As far as sample size is concerned, the goal is to obtain data saturation, which is the point in data collection where new informants bring little or no new information to the study. It is also important not to have too many informants, which could compromise the researcher's ability to undertake deep case-oriented analysis (Crowe et al., 2011; Onwuegbuzie & Leech, 2007). In this study data collection was restricted to informants living in one geographically restricted area (Madwaleni), in addition to people, institutions, groups and organisations providing care for people with psychosocial disabilities in this particular area. In most qualitative research, 15 to 50 in-depth interviews are acceptable, while in multiple case study research it is advisable to limit this to three to six cases (Onwuegbuzie & Leech, 2007; Stake, 2006). There is no clear cut-off point that most qualitative researchers have agreed upon, but it is considered important to collect enough data to have confirmatory evidence from at least two sources, and that the data includes evidence that sheds light on the major theoretical viewpoints in the field of study (Yin, 2013).

For the contextual part of this dissertation I carried out a total of nine group interviews and 25 individual interviews with various health service providers, local leaders, church representatives, and more. For the case study part, I carried out six case studies, which included 11 individual interviews with unique informants. I also consulted two separate psychiatrists.

Most of the interviews lasted for about one hour, but some were longer. For the case study informants, some of them I met on several occasions, interviewed them personally, interviewed several people in their network of support, followed them in their care seeking, and observed their everyday activities. Some of the interviews with health providers were short (15 minutes), others were long (one hour or more). This depended on the relevance of the provider to this project, as well as the availability of the provider. Most health providers were very pressed for time, and could only set aside a short time to talk.

For ease of reference, I have placed lists and more detailed characteristics of all the informants in the results chapters (Chapter 5.2 and Chapter 6.2).

4.5 Community entry

Access to and knowledge of the study setting is key in all qualitative research, and perhaps even more so in case study research. The researcher must know the setting well, but to get to know the setting and the people s/he has to establish trust and cooperate well with the people. It is not enough for a case or an informant to be interesting, s/he also has to feel comfortable and be hospitable with the researcher (Crowe et al., 2011). In a setting like the Madwaleni community access is not just about access to the informants themselves, but access to the community as a whole. This was done through a number of important steps, beginning with ethical clearance, followed by access granted by the Eastern Cape Department of Health. After these two steps were successfully completed, access to the community itself was sought through the paramount chief for the whole area, and then from the relevant chiefs overlooking the areas where we did our interviews. In my first three visits to Madwaleni I was there together with a colleague from Stellenbosch University who had done research there over a longer period of time (Mji, 2013). She is isiXhosa-speaking herself, with roots in the Eastern Cape, and through her doctoral research has become known, respected and had established trust in the community. Her presence in the early stages was crucial to gain entry to the community and facilities in the community. It was important to visit the chiefs on every visit to the community, and on my last visit I was comfortable enough with the community to do this on my own. In addition to the chiefs, we also sought access to visit health facilities and interview staff through management at Madwaleni hospital. This was important not just to gain access, but also to update them on the process and outcomes of our research.

4.6 Reflexivity

> As long as the researchers are not seen as neutral vehicles for representing knowledge in an uncontaminated way. (Hollway & Jefferson, 2013, p. 3)

An important element to qualitative methodologies is reflexivity, which is based on the researchers' recognition that they are part of the social world they are studying and therefore inevitably impact on the phenomena they are researching (Behar, 1996; Griffin & Bengry-Howell, 2008; Holloway & Biley, 2011; Hollway & Jefferson, 2013; Stake, 2006; Swartz & Rohleder, 2008). Subjectivity is an inevitable part of all research, but is more commonly discussed in qualitative research. The researcher impacts on planning, data collection, analysis, data presentation and dissemination through his/her interpretations and presence. This is referred to as reflexivity; the simultaneous influence between the researcher and the informant. For this reason, it is common for the qualitative researcher to use the "I" form in reporting the research, because s/he is inevitably part of the research. Using reflexivity actively throughout the research process is a tool to guard against bad interpretations and help with

good ones (Hollway & Jefferson, 2013). In the following sections I will deliberate on some tools and strategies for reflexivity I have found useful throughout my fieldwork.

Subjectivity must be constantly checked against stories from different informants and the theoretical framework for the research (Hollway & Jefferson, 2013). It is important to acknowledge and be aware that researchers are not blank slates; we come with preconceived ideas and assumptions based on our own experiences, beliefs and culture. It is crucial that researchers move "beyond ourselves" and not let these assumptions influence the research (Holloway & Biley, 2011; Stake, 2006).

While the practice of fieldwork in anthropology is often thought of as a foreign anthropologist participating in and penetrating another culture (Behar, 1996; Munthali, 2001), Behar (1996) argues that it is rather about the anthropologist getting in the way and being influenced by another culture. She argues that the term "participant observation" is an oxymoron, and that one cannot be a participant AND objectively observe at the same time (Behar, 1996). She stresses that what happens in the observer is as important as what transpires from conversations and observations in the field, arguing that "the observer never observes the behavioural event which would have taken place in his absence, nor hears an account identical with that which the same narrator would give to another person" (Behar, 1996, p. 6). Qualitative enquiries are subjective and person-specific, they are impossible to replicate and are therefore unique, irrecoverable and in the past. The write-up is the only proof. It is essential that the researcher is aware of and documents his or her involvement and reactions to the data production and analysis. While anthropologists in the past strived to maintain a boundary between themselves and their research, qualitative researchers today are increasingly arguing that such boundaries cannot be made (Behar, 1996; Holloway & Biley, 2011). So, what can we learn from anthropology? Behar (1996) argues that an anthropologist is one ". . .who has come to know others by knowing herself and who has come to know herself by knowing others" (Behar, 1996, p. 33).

A good qualitative researcher is described as one who is aware and sensitive, rather than overemotional and self-absorbed. S/he is a good storyteller, adding human touches to the research, but s/he is also a scientist producing systematic, collected, transformed and interpreted knowledge (Holloway & Biley, 2011). Researchers need to keep a distance, but at the same time they need to show concern and enthusiasm (Holloway & Biley, 2011). This can be a difficult balance to find. If we are too enthusiastic we may lead the informant into telling us things we want to hear in order to prove what we want to prove. On the other hand, if we are not enthusiastic enough we may not encourage the informant to open up to us and trust us (Holloway & Biley, 2011).

Qualitative research is charged with meaning; meaning to the informant, to the researcher, the reader and the audience. The researcher's job is to interpret the meaning so that the reader and the audience can make sense of it; and in doing so both the insider (the informant) and outsider (the researcher) voices must be heard. But, while the researcher's perspective is important, the main focus of the research should be on the participants' perspectives. But, ultimately it is the researcher who is accountable for the choice of data and for the interpretations made (Holloway & Biley, 2011).

While some argue that similarities between interviewer and interviewee may be important to obtain the best possible results (Hollway & Jefferson, 2013), others argue that differences may in fact be beneficial (Munthali, 2001). Hollway and Jefferson (2013) argue that ideally the interviewee and interviewer should have the same social status, and that differences of gender, race, age, class and so on should be minimized to achieve symmetry in the social identities. Furthermore, they argue that a researcher who has experience and knowledge of the topic they are studying, and who shares the language and culture of the participants, can add to the research from their experience, and the participants may be more forthcoming when an insider speaks to them (Hollway & Jefferson, 2013). On the other hand, this experience and knowledge can shape the researcher's ideology and influence the data; the participants and the researcher may assume that they share the same meaning, when in fact these are just assumptions. The informant may not tell an insider interviewer certain things, assuming that s/he knows of these things being an insider, and as a result important data may be lost (Munthali, 2001). A researcher may have empathy with the participant, but s/he can never fully understand him/her. The qualitative researcher must be careful to never assume that other people see the social world in the same way that they do (Holloway & Biley, 2011). Being an insider, a cultural member permits access to the meaning of others, while it may prevent him/her from keeping a distance to the research and the participants. Being an outsider may assist the researcher to look through the lenses of the participant and help to theorize (Holloway & Biley, 2011). Munthali (2001) argues that whether the researcher is an insider or an outsider to the culture, people will ask questions about his/her role, especially in areas where people are not familiar with research and researchers. He stresses the importance of being honest with informants about one's intentions.

Potential limitations in an interview situation are cultural and ethnic differences between the interviewer and the informant, and their expectations of one another based on these differences (Munthali, 2001; Kleinman, 1980). On the one hand, difference can be positive in an interview situation, as it creates an acceptance and expectation of curiosity and "stupid questions", which may in fact lead to some very crucial findings (Munthali, 2001; Kleinman, 1980). On the other hand, the informant may answer questions in a way that they perceive that

the interviewer "expects". Furthermore, a researcher foreign to the culture s/he is studying may not know how to ask questions that could be potentially crucial, because of lack of cultural knowledge and understanding. I, the researcher in this project, have conducted research both in my "own" culture, as well as in "foreign" cultures, such as for this project. My experience is that while conducting research in a foreign culture requires more work to get to know this new culture and context, the benefit is that I approach each interview with an open mind and with fewer preconceptions.

A qualitative researcher faces many challenges related to him or herself in relation to their research. These are challenges such as maintaining boundaries, developing attachments to informants, managing own and informants' emotions, self-disclosure and leaving the field (Dickson-Swift, James, Kippen, & Liamputtong, 2007). Qualitative research can trigger many thoughts and feelings in both the researcher and the informant, and it is important for the researcher to think through these feelings and other challenges before embarking on the study and also throughout the study period (Dickson-Swift et al., 2007).

Throughout the planning, data collection, analysis and write-up of this dissertation I have kept the abovementioned issues at the forefront of my mind. Thus, issues of my own reflexivity will be raised and discussed throughout the results and discussion chapters.

4.7 Validity

> It is our view that the extent to which a piece of research succeeds in situating experiences within the broader social and political context should determine the credibility and quality of the study. (Van Niekerk & Savin-Baden, 2010, p. 36)

Validity, reliability, trustworthiness, credibility, transferability, consistency and dependability all broadly refer to the same phenomenon; namely an accurate reflection of the studied phenomenon (Morse & Richards, 2002). Validity is the term most commonly used in the case study literature, and the term used in this dissertation.

Gaining validity and assessing the quality of qualitative research can be challenging because the research process is complex, explorative and charged with interpretation (Akkerman, Admiraal, Brekelmans, & Oost, 2008). Researchers' impressions are crucial data in qualitative research, but just as crucial is assurance of those impressions (Stake, 2006). The process of gaining assurance is referred to as triangulation, where one is aiming to find confirmation and assurances for all key findings and interpretations (Stake, 2006). Below are some strategies I have found useful in gaining validity in this particular research.

All interpretations have to be supported by data, and it is the responsibility of the researcher to ensure that interpretations cannot easily be misinterpreted by readers of the research outputs (Stake, 2006). Assurance can be achieved in the following ways: multiple observers of the same phenomenon, second and third perspectives, using more than one research method to study the same phenomenon (documents/interviews/observation) or careful checking of how much the description allows for generalisations (Stake, 2006).

Yin (2013) suggests four tests to establish quality and validity of qualitative research:

1. Construct validity: Used in data collection; use multiple sources of evidence, establish chain of evidence and have key informants read draft report.
2. Internal validity: Used in data analysis; pattern matching, explanation building, address rival explanations, use logic models.
3. External validity; Used in research design; Used to find the domain to which a study's findings can be generalised, theory building.
4. Reliability; Used in data collection; demonstrate how the study can be replicated with same results – study protocol.

Validity, and how it was dealt with in this project, will be addressed further in the discussion chapter.

4.8 Data management and analysis

> The ideal for most naturalistic, holistic, ethnographic and phenomenological case studies is to provide description: Subjective, potentially disciplined interpretation; a respect and curiosity for culturally different perceptions of phenomena; an empathic representation of local settings. Avoiding stereotypes is part of the ethic. Direct comparison is somewhat out of place in such a mix. (Stake, 2006, p. 84)

Hollway and Jefferson (2013) stress the importance of honesty in qualitative data analysis, ensuring that analysis is about enquiry and open-mindedness, rather than judgement and advocacy. It is about making sure evidence is not ignored or emphasised as it suits our research, and it is about being aware of our own reactions to the data.

Analytical categories are to a large extent similar to the questions posed to informants. Categories derived from this research emerged both from theory, as well as from the data itself. Theory and data informed each other at every stage of the project, from the planning to the write-up (Hollway & Jefferson, 2013). Qualitative findings are context bound, and so the analysis must also take into consideration the context where the data was constructed

(Onwuegbuzie & Leech, 2007). In this particular project, the contextual study provided an essential backdrop to the analysis of the case study data.

It is common in case study research to construct theoretical propositions prior to data collection. Theoretical propositions emerge from research literature and form a basis of expected results, theoretically anchor the research, and enhance the researcher's ability to interpret the data and make analytic generalisations (Yin, 2013). In this study few theoretical propositions were constructed prior to data collection, but the research questions were partly theoretically anchored, and hence formed a certain kind of theoretical proposition. The starting point for this study, and for the development of research questions were the fields of psychosocial disability and access to a pluralistic system of health care. Throughout data collection the need for a broader theoretical approach to care and participation emerged, the fields of ethics of care and occupational participation were included, and the research questions and interview guide were ammended accordingly.

In multicase study analysis the cases are interesting first and foremost in relation to the quintain, not in relation to one another (Stake, 2006). In data analysis one should start with highlighting the most important themes emerging from each case, then analyse across cases, and finally make assertions about the quintain and aim to answer the research questions based on the cross-case analysis. Themes refer to central, and usually context (local) bound, concepts of relevance to the quintain. Comparisons are common in all research, and while comparisons occur in case studies, they are of little influence. The goal of multiple cases is not to compare them, but to use each case to provide a better understanding of the quintain. Thick description is more important than simplistic description. Thick description is about exploring multiple perceptions and realities in relation to a quintain (Stake, 2006).

Detailed analytical strategies for case studies are not well defined, and data analysis can be a complex and difficult task. Some techniques to simplify this task have been suggested which I have found useful in the analysis of the data presented in this dissertation (Yin, 2013). One technique is looking for patterns in the case studies that match patterns found in theory. If patterns match, this strengthens the validity of the case study. Another technique is explanation building; building explanations about the case, about happenings, about links and about how these explanations reflect important theoretical propositions. Finally, in a multi-case study such as this one, cross-case analysis is suitable and important. In this approach each case is treated as a separate study, but in addition cases are analysed to see if they replicate or contrast each other (Yin, 2013). Yin (2013) highlights four principles for good case study analysis. First, one has to consider all the data and research questions, and not just the data that strengthens our argument. Second, one must consider all possible interpretations of the data; the

interpretations that strengthens ones' argument as well as interpretations that weaken ones' argument. Third, one must address key issues arising from a case study. And fourth, one must use ones' own expert knowledge about the topic in the analysis (Yin, 2013).

In qualitative studies data collection and data analysis often happen at the same time (Yin, 2013), a method I have found useful in this study, where data collection has taken place over a long period of time and comprises several field visits. This has allowed me to analyse data while I was in the field, between field visits and after all the fieldwork was completed. As a result some of my data collection techniques, tools and analysis strategies changed throughout the fieldwork, and became more and more suited to this particular project and to the particular context.

Data analysis for the contextual study and for the case studies was carried out both separately and concurrently. The data from the contextual study was analysed using thematic analysis, and the broad categories identified through the data analysis is presented in chapter five. Following this, the contextual study was used as a backdrop to the data collection and the data analyses for the case studies. The cross-case analysis, presented in chapter seven, highlights the major analytic categories that emerged from the six case studies, using the contextual study to further explore and understand the culture and context in which the case studies operate.

4.9 Ethical considerations

> [Qualitative research techniques] are. . .the most invasive, intrusive, and morally challenging; the only reason a researcher should consider using them is that the research problem requires them. (Morse & Richards, 2002, p. 29)

Research ethics is about much more than just obtaining ethical approval from the correct ethics committees, although that is also part of it. Research ethics is an ongoing process throughout the duration of a project where the researcher has to reflect on the ethical implications their research may have on their informants' lives (Duncan & Watson, 2010). As mentioned in Chapter 1.3, primary data from this project are part of a larger research project (EquitAble) which obtained ethical clearance from the Health Research Ethics Committee at Stellenbosch University (Ethics reference no: N09/10/270) (see Appendix A). Furthermore, approval was obtained from the Eastern Cape Department of Health to conduct research at the health facilities in the study area (see Appendix C). Some of the contextual data were collected as part of another research project, and ethical clearance for this project was obtained from The Committee for Human Research at Stellenbosch University (Reference no: N08/07/188) (see Appendix B).

A project like this requires attention to the vulnerability of the target group. People with disabilities are among the most vulnerable and marginalised of any population, and many are particularly exposed to exploitation and abuse (Amin et al., 2011; MacLachlan, Mannan, & McAuliffe, 2011; Ruiz-Casares, 2014). In the field of research this vulnerability is potentially twofold. First; the risk of being excluded from being involved in research processes (setting research agenda, developing and carrying out research), and second; the risk of being excluded or exploited as informants in research. The importance of involving vulnerable populations in research has been advocated for by politicians, researchers and user groups, in order to ensure that people with disabilities speak for themselves, rather than being spoken for (Capri & Coetzee, 2012; McDonald & Kidney, 2012; McDonald, Kidney, & Patka, 2013; Read & Maslin-Prothero, 2011). Thus, in the research projects that this PhD is part of, disabled people's organisations (DPOs) have been involved throughout all stages of planning, development and dissemination, to ensure involvement in the research process.

Furthermore, involvement of people with disabilities as informants in research is charged with potential challenges, and thus special care must be taken to avoid exploitation and abuse (Read & Maslin-Prothero, 2011). At the heart of any research project involving human informants is the ethical principle of informed consent. It is the responsibility of the researchers to ensure that all informants meet the criteria for this (Capri & Coetzee, 2012; Nienaber, 2010; Yin, 2013). In the context of poverty, power imbalances between the highly skilled researchers and the often uneducated informants may occur, presenting a challenge to the ethicality of the research (Nama & Swartz, 2002; Ruiz-Casares, 2014). For informants to consent to participation they need to be familiar with their rights. People who are not used to exercising their citizen rights in the first place are more vulnerable to exploitation in research. It is crucial to pay careful attention to the researcher-informant relationship and ensure that informed consent is obtained in a culturally and contextually appropriate manner (Duncan & Watson, 2010; Ruiz-Casares, 2014). In qualitative research issues of consent is a continuous process which should be present in all interaction between the researcher and the informant (Hollway & Jefferson, 2013). While consent is usually obtained before an interview starts, the informant should be informed of his/her right to withdraw the consent or renegotiate the terms for consent at any stage throughout the interview or after the interview. The overall purpose is to protect the informant from harm, and this is the responsibility of the researcher (Hollway & Jefferson, 2013).

People with psychosocial disabilities are regarded as potentially vulnerable to exploitation in research because the nature of their disability may reduce their ability to fully understand the information given to them, and thus give informed consent to participation (Capri & Coetzee, 2012; Nienaber, 2010). It was therefore crucial to ensure that the informants in this project had

the legal capacity to consent to participation. Consent was not deemed informed unless the research participant knew what he or she was consenting to. However, not all people with psychosocial disabilities are legally incapable of consenting to participation (Nienaber, 2010). It is discriminatory to exclude individuals from being informants in research based on an unqualified assumption that they have reduced capacity to consent. Following the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), such exclusion can only be justified through a thorough assessment deeming an individual to have no decision making capacity, which includes inability of supported decision-making (D'Espallier, 2014; Szmukler, Daw, & Callard, 2014; United Nations, 2006). A number of approaches and criteria have been suggested in upholding ethicality in research, while at the same time including persons with psychosocial disabilities as informants. Suggestions include using researchers with particular skills to communicate with such informants, having a guardian or family members present in the interview together with the informant, communicating in the informant's mother tongue and using appropriate words and language (oral and written) (Capri & Coetzee, 2012). To ensure inclusion, the UNCRPD suggests replacing the commonly used substituted decision-making model with supported decision-making, based on people's abilities, rather than their defects (D'Espallier, 2014). In this project this was operationalised through inviting both the primary informant and a proxy to be interviewed together. The proxy, usually a family member, answered the questions together with or on behalf of the primary informant. Two of the researchers in the overall EquitAble project (one of them being the supervisor of this PhD) are clinical psychologists, and they were used as advisors where the informants' ability to give informed consent was in question.

Payment is an ethical issue that has been brought up by many researchers. The question is whether or not one should pay informants for their time and information. On the one hand it can be a mark of respect for their participation, and on the other it can be seen as an incentive which undermines informants' free choice (Hollway & Jefferson, 2013). All participation in this study was on a voluntary basis. No compensation was given to the participants, but most received a small token of appreciation after the interview(s) were completed. They were not told of this token until after the interview was completed to ensure that they did not feel they were getting paid to participate.

Great care was taken throughout data collection to avoid disrupting daily life for participants (practically, financially, emotionally), to ensure that sensitive issues were brought up in a proper and contextually adapted manner, and to avoid creating false expectations. In much social science research some topics and questions may cause stress to the informants, and the question is whether this stress should be avoided, or if it can be justified (Hollway & Jefferson, 2013). Hollway and Jefferson (2013) argue that most social science research comes

with a potential for causing distress to the informant, and that this type of research could hardly survive should such distress be completely omitted. It is crucial that the informants are familiar with their rights, and know that they can withdraw or choose not to answer should the interview bring about more stress than they can cope with. My experience is that most informants, even those that seem terribly distressed in the interview, are happy and thankful to be able to share their stories and have someone listen to them. In interviews that cause stress to the informants, it is advisable to provide informants with contact information for relevant people/institutions the informants can contact should they need follow-up after their participation in the research (Dickson-Swift et al., 2007). In a few of the case studies I experienced the informants becoming distressed and in these cases I advised them to seek help at the closest and most relevant health provider.

Another important ethical principle is confidentiality; informants' rights to be kept anonymous. One way of doing this is to refrain from using informants' real names and/or pictures in transcripts, publications and presentations. Hollway and Jefferson (2013) question whether it is really possible to fully conceal a person's identity, given that each informant possesses a unique set of attributes. These attributes are what make up their story and the data for the qualitative study. Altering this data to conceal their identity may compromise the quality and reliability of the data. Detailed case studies, such as in this project, makes anonymity even more difficult (Hollway & Jefferson, 2013). In this project anonymity was ensured through the assurance of confidentiality of all the informants. This means that the real names of persons, addresses, and so on are not used in any research outputs, or have been substituted by pseudonyms. Most other informants are referred to by their profession or role in the community (nurse/doctor/healer/prophet/reverend/etc.). Staff and management at Madwaleni hospital have expressed a wish for the Madwaleni context to be known in this study and other studies from the area, and Madwaleni has therefore not been anonymised. Madwaleni community, however, is spread out, consisting of a number of areas and villages, and the specific location of case study informants within the community is not mentioned. Some detailed information, such as age, family belonging and other special attributes has been omitted from or changed in the case study descriptions to conceal people's identities as much as possible. Most of the readers of this dissertation or academic publications based on this data will not be able to recognise the informants. I believe that the informants may only be recognisable at community level, and should any members of the relevant communities read this dissertation, that is a risk. This is, however, unlikely. Health providers from the area may read the dissertation, but it is unlikely that informants will be recognisable to them. The information above was given to the informants before an interview. Interviews were recorded when the informants agreed to this, and the recordings were deleted after transcription was completed.

In social science research, particularly in qualitative projects like this one, the relationship between the researchers and the informants are crucial in order to fulfil the moral aspects of guidelines set out by ethics committees (Molyneux et al., 2009). Duncan and Watson (2010) differentiate between moral and ethical thinking. While morality refers to personal values and beliefs guiding self-discipline and respect for others, ethics are ways to regulate morality through norms and principles for behaviour (Duncan & Watson, 2010). It is our moral and ethical responsibility as researchers to ensure that we capture the stories of our informants as truthfully and authentically as possible. The following strategies are suggested to ensure ethical and moral aspects are upheld in research projects; transparency, representativity and reflexivity. Transparency is about making sure that informants know what is expected of them, what to expect themselves and what their rights are (Duncan & Watson, 2010). This can be a dilemma, because on the one hand disclosing too much of the research to informants may taint their responses and jeopardize the validity of the research. On the other hand, the researcher is morally and ethically obliged to provide the informants with enough information to make an informed decision to participate. Furthermore, in the spirit of transparency, researchers should acknowledge their own limitations and insecurities, and their struggles to "do the right thing" by their informants (Duncan & Watson, 2010). Representativity is referring to language and interpretation, and how to capture authentic versions of people's lives. Language influences how stories are understood, especially when the informant and the researcher don't speak the same language. It is crucial and of ethical importance to train the language interpreter so as to minimize limitations caused by interpretation (Duncan & Watson, 2010). Finally, reflexivity, as described in detail above, is about being aware of and documenting factors that influence our data collection, analysis and presentation (Duncan & Watson, 2010).

4.10 Timeframe

Both case studies and ethnographies are time consuming and costly methodologies. They require the researcher to spend a substantial amount of time in the field over a period of time (Stake, 2006; Swartz & Rohleder, 2008). Stake (2006) estimates that for every hour spent gathering data, about six hours are required for planning, negotiating, pondering, writing, explaining and so on. These methodologies are therefore well suited to a doctoral dissertation, where the student is the director, data gatherer and analyst for the study, but with help from an advisor or committee to interpret data and refine research questions (Stake, 2006).

I carried out data collection for this study over a period of six years, and a total of four fieldwork periods, of which I participated in three. Over these six years I spent a total of three months in the Madwaleni community, of which two months were dedicated primarily to the collection of

case study data. The case study data I collected myself, while some of the data from the contextual study were collected by other colleagues from SINTEF or Stellenbosch University.

4.11 Concluding statement

As described in this chapter, this dissertation has used a qualitative methodology, more specifically case study methodology. There are two main data collection components, where the first provides the contextual and cultural framework for the second. In the next two chapters I will present the results from the two data collection components. In Chapter Five I present the contextual results, and in Chapter Six I present results from six case studies.

Chapter Five: Results – Context of care for people with psychosocial disabilities in Madwaleni

5.1 Chapter outline

Chapter Five describes the contextual and cultural setting for the case studies. The results presented in this chapter will be presented thematically. The chapter offers detailed descriptions of the Madwaleni context, the professional health care system, the folk sector health care and the popular sector health care. The description of the context (5.3) includes the location, the physical characteristics of the area, the households, the people, culture, religion, and overall view of psychosocial disability. The description of the professional health care system (5.4) describes the general functioning of the government health care system, as well as how it deals with psychosocial disability. The chapter on the folk sector (5.5) is a description of some traditional healing practices found in Madwaleni; what the basis of these practices are, and how the practitioners in this sector perceive of and care for people with psychosocial disability.

The data for this chapter were collected through in-depth individual or group interviews with the persons listed in the table presented in Chapter 5.2, in addition to notes and observations made by me; the researcher. A number of issues will be touched upon in this chapter that could have been explored in much more depth. Due to the limitations of this study, however, I have concentrated on the issues that I have felt have been the most crucial to the topic of this dissertation, and have therefore had to place a limitation on exploration of issues I have regarded as less important.

In this chapter the terms mental illness and mental disorder will largely be used instead of psychosocial disability. The reason for this is that informants did not use the term "psychosocial disability" in talking about or describing people with mental disorders or treatment for these disorders/disabilities. The results chapter will, therefore, apply the terms that were used and understood by the informants.

This chapter is crucial in providing a contextual and cultural framework for the case studies, which will be presented in Chapter Six.

5.2 Informants

Table 1 below lists the informants interviewed for this portion of the study.

Table 1.

Informants for contextual study

Informants/ Year of interview		
Health providers – Government Health Services – Professional Sector		
1	Physiotherapist (PT)+ Occupational therapist (OT) + Medical Doctor – Madwaleni Hospital (Group interview)	2008
2	Nurse Home Based Care (HBC) Programme - Madwaleni Hospital	2008/ 2010/ 2012
3	Community Health Worker (CHW) HBC – Madwaleni Hospital	2008
4	Nurse Outpatient Department (OPD) – Madwaleni Hospital	2008
5	Nurse - Vukukhanye clinic	2008
6	Nurse - Xhora Health Center (HC)	2008
7	Nurse - Xhora HC	2008
8	Care givers (2) - Xhora HC (Group interview)	2008
9	Nurses (3) - Nkanya clinic (Group interview)	2008
10	Care giver - Nkanya clinic	2008
11	CHW – Nkanya clinic	2008
12	Nurse – Soga clinic	2008
13	CHW Orphans and Vulnerable Children (OVC) Programme – Soga clinic	2008
14	Nurses (2) – Mgele clinic (Group interview)	2008
15	CHWs (7) – Mgele clinic (Group interview)	2008
16	Acting superintendent – Madwaleni Hospital	2010
17	Hospital manager and superintendent – Madwaleni Hospital (Group interview)	2010
18	Physiotherapist – Madwaleni Hospital	2010
19	Nurse and acting hospital manager – Madwaleni Hospital (Group interview)	2011

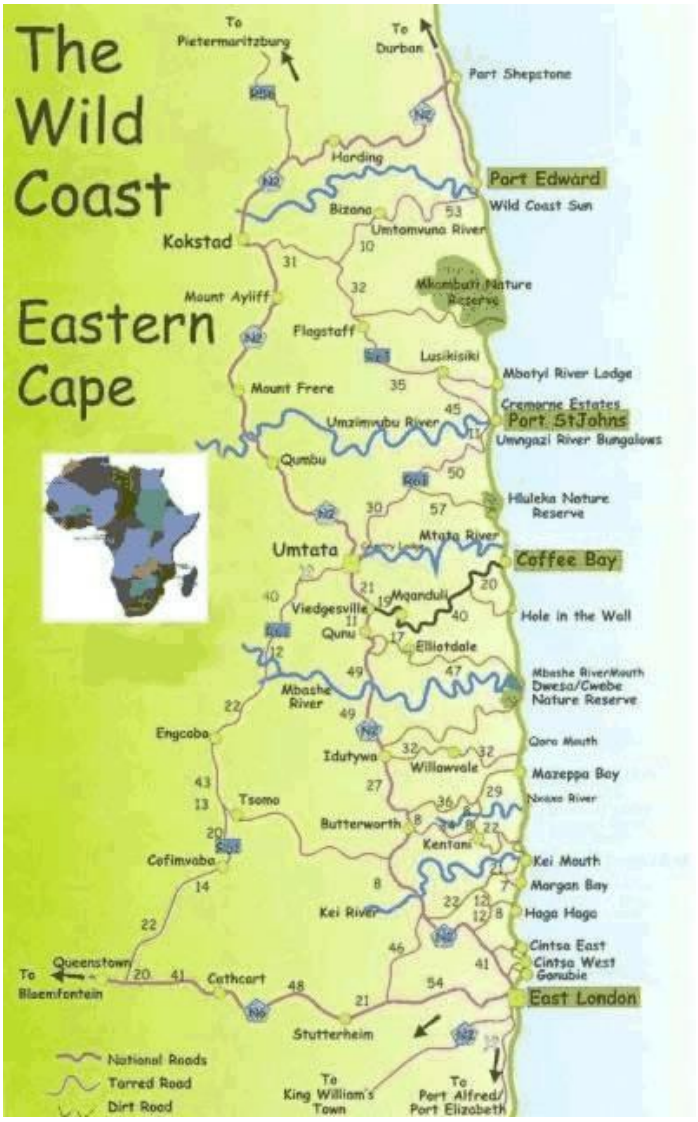
20	Nurse OPD – Madwaleni Hospital	2011
21	Nurse – Hobeni clinic	2011
22	Nurse General Ward – Madwaleni Hospital	2011
23	Manager OVC – Madwaleni Hospital	2012
24	Representative DWF – Madwaleni Hospital	2012
25	Psychology Intern (Walter Sisulu University) – Madwaleni Hospital	2012
26	OTs (3) – Madwaleni Hospital (Group interview)	2012
27	Nurse TB Ward – Madwaleni Hospital (Used to run psych clinic at the hospital around 1995)	2012
Health providers – Folk Sector		
1	Traditional Healer - Faith (St. John's Church)	2011
2	Prophet (old man) – Ancestors/Zion Church	2012
3	Prophet (young man) – Ancestors/Zion Church	2012
4	Traditional Healers (2) – Ancestors	2012
Churches - Popular Sector		
1	Reverend – Presbyterian Church of Africa	2012
2	Reverend – United Christ Ministry	2012
NGOs - Popular Sector		
1	Manager – Home for people with special needs (charity-based)	2012
Local Governance - Popular Sector		
1	Chief	2010
2	Chiefs (2) and assistant (Group interview)	2010
3	Paramount chief	2010
	isiXhosa-speaking academics	
1	Stellenbosch University academic (SUNA1)	2013
2	Stellenbosch University academic (SUNA2)	2013

5.3 Madwaleni community

Over a period of five years I spent a total of three months in the Madwaleni community, in addition to learning about the community and communicating with key people from the community throughout the five years. I have thus gained a degree of in-depth knowledge about the community, having had the opportunity to study the community both intensely during the three fieldwork periods and also over time.

This section will describe the Madwaleni community; the location, the physical characteristics of the area and the households, the people, culture, religion and overall view of mental illness. The results in this section are gained through observations, informal conversations and interviews with chiefs, representatives from NGOs and religious leaders.

5.3.1 Location



"Madwaleni" refers to a hospital catchment area located in a deep rural area of the Amathole District in the Eastern Cape Province of South Africa. This part of South Africa is popularly known as the Wild Coast area (see map in Figure 3[4]). The hospital is situated in the middle of the community, approximately 30 km from the nearest town, Elliotdale, 50 km from the N2 (national highway), 100 km from Mthatha (Umtata on the map), 220 km up the coast from East London and 16 km from the coast. Madwaleni Hospital catchment area stretches from the coast to Elliotdale, bordering the Mbashe River in the south, stretching slightly north of the Xhora River in the North.

Figure 3. Map of the Wild Coast area, Eastern Cape

[4] Map from: http://www.cederberg4x4.co.za/wildcoastmap.htm

5.3.2 Physical characteristics

Figure 4. Madwaleni terrain

While the distances in kilometres between the hospital, clinics and towns are not large in this area, the time and effort required to travel between the different locations are very challenging. The area is characterized by hills, valleys, rivers and tributaries, streams, forests, narrow paths and unpaved gravel roads (see Figure 4 for picture illustration of the terrain in Madwaleni). The roads are of poor quality at the best of times, with loose gravel and pot-holes. During the rainy seasons many roads become impassable due to flooding of the roads and the gravel turning into slippery mud. During my stays in Madwaleni I used rental cars to get around, and as a result I got to experience the Madwaleni roads first hand. The rental cars were 4X4s and/or pick-ups ("bakkies" in South African parlance), new and in good condition. On numerous occasions I had to turn around and change/cancel my plans as the roads were impassable. Sometimes rivers had risen so much that they flooded over bridges and roads, and other times the roads were so muddy and slippery that even a 4X4 could not climb up the smallest of hills. Adding to that the roads are very damaging to the cars, and during the course of my three fieldwork periods I experienced cracked windscreens due to falling rocks, flat tyres (three times) and a broken gearbox.

There are a few cars, bakkies and vans operating as "public transport" (unofficial) in the area. These primarily run along a few major roads from early morning until about 5pm. People who require transport stand alongside the roads and wave when a car approaches. If the vehicle has space available, it stops and takes people on board. This is not public transport as such, but vehicles owned by private persons who operate them as public transport. The fee for the transport depends on the distance of travel. These vehicles can also be hired as taxis, but at a much higher cost.

Rainfall is heavy in this area, mostly in spring (August – October) and autumn (February – April), but also with thunderstorms in the summer (October – February). For most parts of the year Madwaleni is lush and green, and during heavy rainfall rivers and streams often flood, making roads and paths impassable, and as a result some parts of the community get cut off from its surroundings.

A representative of an NGO operating in the area said that the bad quality of the roads often makes it difficult to get anything done, especially during heavy rainfall. As a result, many people are completely trapped at their home; they cannot travel anywhere, as the car will not be able to travel on the steep and slippery road. The nearest clinic is a 30-minute walk away, but they have to cross a river, which often floods and is difficult or impossible to cross after heavy rainfall. This situation is similar for many households in the community.

I noticed that there are substantially fewer people out when it is raining. I wrote in my field notes:

> *What strikes me about this place is that the community does seem to "go to sleep" and stop most activities when it is raining. Everyone seems to agree that if it is raining things should be cancelled. Khaya (my interpreter) was saying that he was worried about it raining this weekend, as there were so many things going on, and he did not know how they could be done if it is raining.*

There is scarcity of sewage systems, running water and electricity to the general Madwaleni community. I have noticed, driving through these areas, that the communities closest to Elliotdale and the N2 national highway have over the past five years have developed in terms of building of pit latrines, roads and improved housing. I was told of a government project involving the building pit latrines in rural households. The communities furthest away from town, however, had not yet benefited from the pit latrine project, and most households had very basic toilet facilities, if any. It seems that any developments in this area; pit latrines, roads, clinics, etc., start closer to the town centres, and many parts of Madwaleni are simply too far away from any town centre.

After an interview I described the setting for the interview in my notes, a setting that is typical for much of the Madwaleni community:

> *During the interview today we sat outside, while chickens, cows, sheep and horses were wandering around. From their plot of land we could see rolling hills on all sides, with colourful rondavels scattered around on top of the hills, flowing rivers at the bottom of the hills, and the big blue ocean in the far distance. Driving along the roads to get here we saw women, men and children walking from their day-to-day activities, or waiting for a car to pick them up. We also saw cows, goats, sheep, donkeys, chickens, pigs and horses, roaming around freely and blocking the roads on a regular basis. Some of the plots here have lush vegetable gardens, but not all. There are some health programmes in this area that focus on gardens and growing vegetables, such as the OVC programme and the HIV programme. Most people do look fat, and being fat is seen as a sign of being wealthy and healthy by people in this community. On sunny days like today some people walk around covering themselves with big umbrellas, while others smear mud on their faces to protect their skin from the sun.*

An average plot in Madwaleni consists of a few rondavels (round homes) made from mud and cow dung and with a thatched roof. The size of a rondavel is +/- 10 square metres (see Figure 5 for picture illustration of the interior of a rondavel). Some households have designated rondavels for sleeping and cooking, while others only have one rondavel where all activities of daily life are carried out. Some plots have square houses made from bricks and cement, and with iron sheets as roofs. These houses are more expensive to build. Many households have plots of land where they grow vegetables, in addition to animals such as cows, sheep, pigs, chickens, goats, horses and dogs. Most of these animals are free running, but I was told that they return to their “home” for food and care on a regular basis. I have visited many Madwaleni homes throughout the course of my fieldwork, and my impression is that while sparsely equipped, houses and plots are generally well kept; clean and tidy. Most people sleep on mats or thin mattresses on the floor, while some have beds. Food is cooked on a small paraffin cooker or on a fire.

Figure 5. Interior of a rondavel

Most households do not have electricity and water. Water is collected from the rivers and streams.

A few people have told me the reasoning behind the round shapes of the rondavels, and the main theory is that this is to keep the snakes out of the house. When snakes come in they look for a corner to hide in, and they will move along the wall trying to find a corner. In a round house they will automatically end up at the door again, and go back outside. Another theory is that the houses are round so the children will not be able to find any corners to defecate in. Furthermore, I was told that the purpose of the tyre many huts have on top of their thatched roofs, is to keep away bad spirits. There is a tyre, and it has pieces of glass and other things sticking out at the top (see Figure 6 below for picture illustration of the exterior of a rondavel).

Figure 6. Exterior of a rondavel in Madwaleni

The Hobeni area is one of the areas of Madwaleni the furthest away from the hospital, from Elliotdale and from any town/commercial/trading centre. It is one of the least developed areas of Madwaleni. One good thing benefiting some people in the Hobeni community, however, is the employment offered at the Haven Hotel. The Haven is the only hotel in the community. It is located inside the Dwesa/Cwebe nature reserve, on the Wild Coast. Some households have

family members employed at the Haven, and this is of great economic importance to those households.

5.3.3 The people

The people of Madwaleni belong to the amaXhosa tribe, more specifically the amaBomvana sub-tribe. Below the sub-tribes there are smaller clans. According to contemporary constructions of amaXhosa culture and traditions, the area is governed both through an amaXhosa governance system, as well as the South African governance system. In the amaXhosa governance system the overall leader is the paramount chief. In Madwaleni the paramount chief is a woman, and she oversees a large area. Under her are chiefs overlooking smaller areas, which again have chieftains under them. In the South African governance system, it is the district counsellor who resides over the whole area. I was told that the placement of the district counsellor and the collaboration between the two governance systems is problematic, but due to the limited scope of this project I have not gone into detail on these issues.

The majority of the people in Madwaleni are unemployed, or at least without official employment. There are very few official employment possibilities in Madwaleni, and as a result many men work outside the community, often in mines in towns and cities far away. This results in many women-headed households, as the men are only present in the household a few times a year. Due to the HIV/AIDS epidemic there are also many grandparent- or child-headed households.

I have noticed when I interview people in households here, and I ask them how many people and who live in the household, this information changes throughout our conversation. When I ask the question they will count and think and name those who live there, and then often in conversation or in person, throughout the interview, other people will come up, or walk in, and they also live there, but they were not mentioned or counted when I first asked the question.

5.3.4 Poverty

People in Madwaleni own the plot of land that they live on. The land is initially given to them by a local chief, and is then passed on in the families. The land is green, lush and fertile, and many people make the most of this with big vegetable gardens and fields of crops. Despite this, the people of Madwaleni are generally considered to be, and consider themselves to be, poor. It is a community that has historically been self-sufficient but is increasingly dependent on monetary assets. While social services, such as health care and education, are “free”, there are costs required to access these services. These costs are related to transport, hospital fees,

school uniforms and equipment. Also in everyday life people have become more dependent on money to buy paraffin for cooking and food items. For most families their main source of income is from social grants such as child support grants (South African Rand[5] R280), old age pension (R1200), disability grants (R1200) and foster care grants (R770)[6]. A household of 5 - 7 people will typically survive on a couple of small grants (such as a child support grant) and one of the larger grants (old age pension). To put this into context I checked the prices of a few normal household items in the local shop (prices from 2011):

- Bread: R6.00
- Tomatoes (10): R10.00
- 2 l. Fish oil: R30.00
- 12 kg. Sugar: R105.00
- 12, 5 kg. Flour: R90.00
- 12, 5 kg Mealie Meal: R69.00
- 1, 5 l. Coke: R10.00
- 1 l. Paraffin: R8.00

Most people have to use public transport (as described above) to get to their local clinic, to the hospital or to the nearest shop. Transport is a big cost for people, even if the cost is as little as R10 one way. When people visit health care services, for instance, they are often accompanied by a family member. A return trip to the clinic, for two people, will end up costing at least R40. To get to Madwaleni Hospital for people living in a community further away, it seems that most people hire a car with a driver for the whole day, which costs approximately R400. There is public transport, which is a cheaper option, traveling up and down the main roads, but few cars travel directly to Madwaleni Hospital from some of the more distant places such as Hobeni, as the quickest road to the hospital is a short-cut that is a very bad road, impassable to small cars at the best of times, and to all cars when it has been or is raining.

5.3.5 Health

Physical health

Water is a major health issue in Madwaleni. One chief believed that people are getting sick due to the poor quality of water and accessing water that has been infected with human waste washed down to the water sources during the rains. As a result, diarrhoea is a common health problem in the area. Another chief said that he feels that young people are the most vulnerable

[5] One South African Rand (ZAR) equalled about 0.1 USD/ 0.07 Euros at the time of the study: http://www.xe.com/currencyconverter/#

[6] Amounts of grants per month as of 2012: http://www.sassa.gov.za/Portals/1/Documents/05283ff8-ef75-4869-94b6-c026334269ef.pdf

in the community because of the HIV epidemic. The greatest challenge, in his opinion, is the issue of disclosure; people get infected and they do not immediately disclose, and as a result put even more people at risk of infection. Movement of people back to the community is a key issue, especially men who go out to work in the mines returning to the community HIV positive. Another chief believed that the rapid spread of health conditions currently was in part due to the expanding population, and new patterns of living. He recalled that in the past housing was spread out and the spread of health conditions was more controlled. However, with the current density of housing the spread of health conditions is not easily controlled. Some of the health conditions he stated as being on the increase included TB and diarrhoea. The chief also recalled that the health of the mother and child was protected in early days by community practices. One such practice was that of pregnant women visiting their parental home to bear the child, and staying there until the child was three years old before returning to their marital home. This allowed for a natural break in child bearing as well as maternal and child well-being. Practices like this one are no longer common.

Epilepsy, or fits, is a widespread problem. This could be due to tape-worms which people can get from eating contaminated pork, leading to neurocysticercosis, which again can lead to epilepsy. The condition and symptoms of epilepsy are charged with cultural beliefs, especially beliefs as to what causes the epileptic fits. It is my impression that people in the community are generally not familiar with epilepsy or neurocysticercosis, but they are very aware of people having seizures or fits. The information given to me about epilepsy was from skilled health workers.

The major health problems people in the community talk about are high blood pressure ("*ihighhigh"*) or diabetes (“*sugar”*). When they suffer from some symptoms of illness they go to the clinic and get tested (or so they think at least) for these things. And then they go home with "no *ihighhigh*" and "no sugar", under the impression that the professionals at the clinic do not know what is wrong with them (again, these are perceptions of the patients). It seems that Panado (paracetamol-based medication for pain relief, commonly used for headaches) is a commonly prescribed drug to people with some "head problems" (including mental illness), whether they have a headache or not. The assumption from the patients being that because the problems are in the head, Panado must help.

Mental health and disability

I was told by a number of informants that in the amaXhosa culture people believe that they must get married to someone outside of their own clan, or any clan they are related to through parents and grandparents. If they do not obey this, the ancestors will get angry and punish them, for example by giving them disabled children.

One issue that comes out strongly from all my data is the issue of jealousy. Many people spoke of jealousy in this community. Jealousy is generally directed at people who are materialistically successful. If people are doing well, making money, building new houses, upgrading their property or land, buying livestock, and so on – this makes people jealous. I was told that jealousy commonly leads to witchcraft. Jealous people bewitch the people they are jealous of, and this leaves the bewitched person afflicted with any kind of sickness, including the sickness of "madness". Anyone can be jealous, and hence anyone can be bewitched. My interpreter, Khaya, repeatedly told me that jealousy is very bad, and does no good to people or to the community. It causes a lot of pain, as people can be mean and unreasonable when they are jealous. In interviews and conversations with church leaders, the issue of jealousy also arose. I was told that it is a phenomenon which is very present in the community, but in church it is discouraged:

> *We try to teach them not to be jealous. Some are less educated, poorer and so on, but we try to convince and tell them that all people are the same before God.*

During my last fieldwork trip, Khaya commented that many children get sick during exam time, because around that time many children were attacked by evil spirits. These evil spirits can make the children's minds go blank or tired when they are writing their exams, or it can make them get ill or irritable. Khaya explained that evil spirits are brought on by jealousy. Anyone can bring evil spirits on another, but it depends largely on upbringing and faith if people do it. If someone goes to the traditional healer to get rid of the evil spirits, the evil spirits will go back and attack the person who sent them in the first place.

It comes across in interviews and conversations that displays of grief or sadness or negative feelings are not very well accepted. People believe that these feelings are somehow contagious; other people will feel these negative feelings if they are displayed openly. Thus, a common reaction is to ask people to contain their emotions. I attended a funeral in the community, and it struck me that throughout the few hours that I was there I did not see one person crying. People looked serious, and there were less smiles and laughter than normal in the community, but there was no crying for as a long as I was there.

5.3.6 Religion

In Madwaleni there are both religious and non-religious people. Those who are religious belong to a variety of Christian congregations. A reverend from the Presbyterian Church of Africa spoke of the divide between the believers and the non-believers:

> *There is a community of faith believers and a community of non-believers. It is difficult for these communities to go along the same road. It creates problems, a conflict between the non-believers, who believe they can be saved by ancestors, and believers who believe Jesus is their saviour. To bridge these two is difficult.*

Many of the Christian congregations have formed societies or groups for different groups of people, such as women's groups, men's groups, youth groups, couple's groups and so on. These groups are known as *"manyanos"*. The manyanos get together for church services for that particular group only, for training/education/counselling or for social activities. The manyanos get together on a weekly or monthly basis. For many people the manyanos function as a support system. The groups are small enough so that people know each other, and can alert each other about things, help each other, and can together approach the leader for help if necessary. I was told that if someone recognises that a person in their manyano has a problem with mental illness, the participants in the manyano will try to help. Sometimes the manyano participants or the leader is help enough, and sometimes they may take the person to see a doctor, a psychiatrist or a social worker. Manyanos can also work as preventive mechanism against mental illness and related issues. For instance, in couple's groups they teach married couples how to live together, how to be happy at home. A reverend from the United Christ Ministry explained how they do it in his church:

> *Here there are some happy in their marriage, and some are happy at church, but not at home. If the wife is in church, and the husband is not it causes conflict. We call the wife to counsel her and pray for her, asking God to assist. The conflict is because in most cases it's not easy for the male to be believers, but women are in church, and that causes conflict. We have a system we work with to the couples. We write a letter for every couple belonging to the church. This is for the wife to take to the husband, to invite the men to a special service. After that service (preaching/singing for their benefit) we counsel them to understand the church, and this sometimes makes them come to the church. The lesson we teach the female on how to convince their husbands is to teach women their dignity; to be a respected woman. If the female is rude, it is not easy for the husband to be convinced by her. A dignified woman is an obedient woman who is obeying and loves her husband. As you know, especially in African culture, men like to have other women outside (of the home). We tell her not to show, but rather pray to God to convince her husband to come back. We encourage and teach the woman not to stop the man if he wants to go out, but rather treat him well at home, giving him water, iron his shirts, and tell him to go. This will make him wonder what is going on at home, why she wants him to go, and he will return home.*

Furthermore, in youth groups, young people are taught how to be good to themselves and others:

> *We teach them ways of self-conduct, self-respect, self-known and self-worth. Boys and girls are both in these groups together. We start as a youth group, and then we part into two parts; boys and girls separately. We teach them, as some are poorer, some are richer, some believers, some non-believers; we teach them not to laugh at each other's differences, but to assist them not to be ashamed, but to pray to God to assist them, for example, not to be poor like their parents. They should not feel bad or ashamed of being poor.* (Reverend, United Christ Ministry)

The churches also have children's groups, or Sunday schools, and here children are taught how to be good Christians and how to look after themselves:

> *We grow them to God, the word of God and to pray for God. We also teach children to come and attend church; it's their home of living and happiness. God is only a helper of their life. We teach them the word of God and to know what is happening in their home. Some are a bit mature. We tell them to not discourage someone, and don't disgrace yourself. We also teach them to speak up if they are abused sexually. This happens often, and they are threatened not to tell. The teachers tell them and encourage them to tell us. We have never actually experienced this, but if it can happen, we need to protect the child, and take steps towards the law; police, social workers, doctors. We need to find out what happened, so the person can be caught and arrested, and see if the child has got any illnesses and infections, and so on. The people at the church can be witnesses in court.* (Reverend, United Christ Ministry)

In addition to health/mental health prevention and promotion, several churches also take on healing and treatment responsibilities. I was told that especially the Zion church has healing practices where they treat illnesses related to witchcraft. In the Methodist church I was told that there are certain people in the church who can heal people:

> *It is sort of like a healer with prayer; she prays for people who are mentally ill or who struggle with mental problems. She, for example, visits people who have problems at their homes or at the hospital, and she prays for them to help them get better.*

There is no formal collaboration between churches and government health care services in Madwaleni. Some of the churches provide their own healing practices, such as the Zion church, which will be described in more detail in Chapter 5.5.

5.3.7 Views on psychosocial disability

I asked my interpreter, Khaya, to translate a few English terms related to psychosocial disability into isiXhosa for me. I also asked two academics from Stellenbosch University, both first language isiXhosa-speaking, to translate the same terms, and to comment on the translations made by Khaya. One of the academics was in the field of African languages, the other with a background in physiotherapy, both with a PhD. I deliberately chose people who are not experts in psychosocial disability because I was interested in the general meaning of the terms, rather than how they are understood in psychiatry. Table 2 below presents the terms in English, along with the isiXhosa translations made by Khaya and the two academics. I have also added some comments from the academics in brackets.

Table 2.

English/ isiXhosa translations of psychiatric terms

English term	**Khaya translation**	**SUNA1 translation**	**SUNA2 translation**
Depression	***Uxinzelelo*** (SUNA2: This means "when you are pushing or pressing, or something is difficult, when you are trying to expand or explain, or you are emphasising on something." Would not perceive it as depression at all)	***Uxinzelelo***	***Ukungonwabi okubheke ezantsi eyenzeka ixesha elide*** (Deep unhappiness/ sadness that lasts for a long time)
Mental disorder	***Uphazamiseko engqondweni (uphambene)*** (SUNA1: Refrain from using "uphambene")	***Ukuphazamiseka engqondweni***	***Ukugula ngengqondo*** (Your mind is sick) ***Uphazamiseko engqondweni*** (When mind is disturbed or you are mad)
Hallucination	***Ukubanemiwa ndedwa*** (SUNA2: This is a proverb for stealing, while "Ukubanomva ndedwa" translates to "loneliness, felling lonely, sad")	***Ukuba nemiva-ndedwa***	***Ubona izinto*** (You see things that are not there, or feel things that are not there)
Schizophrenia	***Ubugeza kungekho luncedo***	***Ubugeza kungekho luncedo***	There is no proper term for this in Xhosa, would be a more descriptive sentence: ***Uhlobo***

	(SUNA2: This translates to “being mentally disturbed without any help”)		***oluthile lokuphabhana uludibene nokuzibona usenza izinto ongenakuzenza okanye ongazange uzenze- bona izinto ezingekhoyo*** (You see things that are not there or you think you can do things that you cannot do, or are things you are not)
Psychosis	***Ufuna unyango lwentuthuzelo, empefulweni*** (SUNA2: This translates to “someone that requires to be helped for illness, something that is going to heal his soul, make him feel better”)	***Ufuna unyango lwentuthuzelo emphefumlweni*** (SUNA2: This translates to “to get help from a dark spot that they are in”)	***Luhlobo lokuphambano*** (A form of madness)
Manic	***Ukucinga ukwenza into ongenaco ukuyenza*** (He explained the meaning of the translation with: “You think you can do something but you can't”) (SUNA2: This means “to think of something that you can't do”)	***Ukucinga ukwenza into ongenakho ukuyenza***	***Ubudlongo- dlongo obukwenza wenze izinto ongakwazi ukufikelela kuzo*** (Being over excited and makes you do things that are beyond your capabilities)
Substance/ alcohol/drug problems	***Ubunxila*** (drinking alcohol)/ ***Iziyobisi*** (drugs)	***Lingxaki zotywala/zeziyobisi***	***Ubunxila / Iziyobisi*** (alcoholism and drug abuse)
Nervous	***Ingcinga edinwayo*** (He explained the meaning of the translation with: “Thinking too much with no outcomes of thinking and ending up tired’') (SUNA2: This means “thoughts that are depressive or saddening”)	***Ukungazinzi***	***Ukuba nentaka okanye okoyika kungekho ifanele ukukoyikisa*** (To be afraid or anxious when there is no reason to be afraid)
Happy	***Ukonwaba***	***Ukonwaba***	***Ukonwaba***
Unhappy	***Ukongonwabi***	***Ukungonwabi***	***Ukungonwabi***

In the translations above we see that while there are some discrepancies in the translations, there are also many similarities. Some of Khaya's translations may not be the optimal

translations for specific mental disorders, but the meaning of the English and Xhosa words are similar enough to determine the relevance of his translation for this project.

The concepts of psychosocial disability, mental illness and mental disorder are complex and, for many people in Madwaleni, difficult to understand. During my first two fieldwork trips in Madwaleni, I struggled to make people understand what kinds of informants I was looking for in my study. Several times I was taken to interview people with intellectual disabilities, thinking that this was what I meant when I said I wanted to talk to people with mental illnesses/disorders/psychosocial disabilities.

Towards the end of my last fieldwork trip in 2012 in wrote in my field notes:

> *In many interviews we have spoken about the concepts of happiness, unhappiness, feeling worthy and depression, and it strikes me that for many people these concepts are largely linked to practical and economic well-being. I have to look into the direct translation (Khaya's translations above) of the concepts from English into Xhosa, to see if Khaya's translation itself is what leads them to these answers. But from what we have heard so far being happy is linked to having enough income, and not having to worry about money. Depression for the one lady was linked to her worries for her sick and mentally ill mother, especially worrying that the mother may run away if she is not being watched.*

I asked church leaders what their perceptions of these concepts were, and their understandings were closely linked not only to their beliefs, but also to more traditional cultural beliefs. A reverend in the Presbyterian Church of Africa said:

> *Mental health are spiritual problems; people possessed by spirits. As a church we must be careful, as spirits disguise themselves in many ways. The Bible says that we must look at them and see if they are good or bad spirits. People who are possessed by spirits must obey Jesus.*

Similar dichotomies can be found in the explanation by a reverend from the United Christ Ministry who believed that there are two major categories of mental illness; one caused by stress and one caused by evil spirits. He explained:

> *Mental problems; we have such things. Maybe not actually mental illness, but a person has been attacked by the nerves, and you can be a slow thinker. Maybe because of home sexual abuse, or those things, lack of money or attack by evil spirits. We do encourage people to understand the difference between sicknesses. One can be mentally ill because of evil spirits, OR one can be mentally ill because of stress, caused*

> *for example by thinking one is HIV positive or has TB. For people mentally ill because of stress, we pray for them and encourage them to take the hospital treatment. Evil spirits and stress are two different mental illnesses, and it's easy to differentiate between the two. It's easy to identify a person attacked by evil spirits or someone being stressed because of HIV, poverty or other things. We see if this person has been abused, see if someone is pulling away, not singing in church, always quiet and shy.*

On his understanding of happiness, the reverend from the Presbyterian Church of Africa said:

> *How can someone be happy? That's where you need groups like manyanos; we sing songs to raise the spirit of this person. To be happy, someone must be in good company with people who care for other people. What is the use of surrounding someone with people who don't care?*

His thoughts on depression were as follows:

> *It is possible that it is there, but Africans (Black) do not like people who enquire about their health. For example, we have just come from a funeral, and it is possible there are people who are depressed. But they don't like for us to enquire about that. Culture may have a role in making people depressed. I believe that a person must be allowed to cry, and deal with that. If you say for someone not to cry, it will make them depressed. At a funeral, at the day of the burial, we don't like to hear people cry; they must keep it in. But we (referring to himself and Khaya, who was also present) think it is good to cry, and let things out. At funerals people stop others who cry; "Don't disturb! Stop that!" We don't like it; people crying out loudly. They believe that while you cry, you make other people cry as well, and it will be disturbing.*

In relation to this I wrote the following in my field notes in 2012:

> *People keep saying to me that "these people" don't have a tradition for talking about things. Talking about problems and sorrows is not common; they just get by in silence. They don't believe in talking about things. Khaya also mentioned this in relation to the sad girl we spoke to the other day, when I asked her if she talked to anyone about her sadness. He said that she should talk to one, maybe two people, but not so many people, as she will lose part of herself if she talks to too many people. The question then becomes; can they be taught to talk and to believe in this talk, or is talking not for them. Will talking in the form of counselling and psychology even be beneficial to them?*

The reverend in the Presbyterian Church of Africa spoke of the link between HIV and mental illness. People diagnosed with HIV experience shock and stress which can cause mental

illness. In these cases the church provides counselling, or approaches psychologists or social workers for assistance. The reverend also explained that mental illness is caused by drugs, stress and anxiety, and that prevention of mental illnesses should be the responsibility of health workers and social workers:

> *They should come to the clinics where it is better to get many people, and explain the causes of this illness, how to recognise these people. It is common for people with this illness to hang themselves. They must have professional help. Therefore, they must visit the clinics to teach them what to look for so these patients can get help.*

The reverend feels that drug use is closely linked to mental illness, especially among young people:

> *Youngsters must be taught to do away with these drugs. When you use you become bit by bit mad. They use drugs like Nyaope (like cocaine), sniffing petrol, dagga and alcohol. This problem must be dealt with by the headman. Even at school there are some taverns close by, and they should not be so close to schools. They should restrict opening times, as now they are open 24 hours. And people don't comply with age limits, and serve alcohol to very young children. So the taverns are also the source of that kind of illness. It is mostly kids that drink and use drugs, and it is difficult to persuade someone to stop using.*

Among both youth and adults, the reverend's experience is that unemployment causes poverty which leads people to regard themselves as someone who cannot do anything for themselves. This again causes family problems, and makes people use drugs. In his church they try to persuade members to keep their eyes open for these problems:

> *I do not think people in church drink, but it is an evil thing, so people will hide it. It is linked to evil spirits and demons. Some worshippers will pray, but people possessed by evil, they will pretend to be praying, but will not really be praying.*

One of the church leaders told me that they had recently had a member of the congregation who committed suicide:

> *Suicide happens. We do have one in our church. She was a widow. We came back from Good Friday service. While we were at the service we were teaching them the word of God, talking to all members of the church. She used to come to the front, kneeling to be prayed for. We wanted to know why she does this, but she doesn't tell the truth. When we came back from the service on that day she had hung herself. We don't know why. It was difficult for the family and for the congregation to accept it. As a*

> *congregation we visited the family after the suicide, praying for them, counselling them to accept. The family was open about it being suicide. She hung herself at home in the rondavel, from the ceiling. Her children found her. She was about 54 years. Most people are open about suicide. It's common. When we counsel the family, first, for them to understand, the pastor must teach them to know about the death, and to understand and accept it. Like even with water or the egg; If you hold an egg in your hand and you lose it, then you don't have an egg anymore. You must let go. If someone is dead, they are gone, they will not come back, and they must accept. We talk about life after death when someone has lost someone – it helps them. We believe that through the preaching of the gospel the word of God goes through that person's mind. That's when he can make the decision to repent and follow.*

Most of the informants for the case studies were identified through Khaya, and he seemed to have a good idea of what kinds of people I was looking to interview. He came across as being a very accepting and understanding man, but on one occasion we had an interesting meeting with a supposed “mad” woman, and I wrote in my notes:

> *As we were driving back from the prophet's place near Breezy Point today, we drove past a woman who was pointing at the car, waving and yelling something. I slowed down to perhaps give her a lift, as we had picked up many people for lifts on our way there. For the most part Khaya tells me who I should pick up and who I should not pick up. He told me the other day that I am not a taxi, so I don't have to stop for everyone, but then every now and again (often) he tells me to stop and pick up certain people. The road to Breezy Point did not seem to be frequented by taxis, and even if it is, today the road was particularly bad, and most cars would not be able to pass. Anyway; as we passed this woman, and I slowed down, Khaya instructed me to “just keep going, just keep going.” So I said, “Oh, ok. I thought she might need a lift”, whereby Khaya replied something along the lines of “this woman is crazy, mad, and if we were to pick her up, she may not want to get off again, and we don't want to struggle with that”.*

Evil spirits were cited by many informants as one of the major causes of mental illness. I asked the church leaders how they knew that someone has been possessed by evil spirits, and the reverend from the Presbyterian Church of Africa told me that there is a practice called *"muthi"*. In muthi people use herbs and other things out of witchcraft and use these to bewitch another person:

> *We see evil spirits manifesting; foaming at the mouth, twitching, hearing voices. If you follow these voices, you see they have got nothing to do with God, they are evil spirits. We have some people who exorcise those evil spirits. Members of the Zionist church*

> *perform such miracles. Anglican, Methodist, Presbyterian and Roman Catholic believe in Catholicism, and don't do exorcism. Spirits are demons by nature, if you exorcise those they can take over you. By associating oneself and practicing witchcraft and occultism, you might end up with the spirit. You can't play tricks with the spirit. Some of those herbs are bad and can make you be possessed. Witchcraft is not practiced publicly. You will not see it. You just see the result. Some herbalists claim to have the power to see the supernatural. I don't know. . . . When you approach a person using herbs, you end up in a sphere of evil spirits. It's difficult to remove those spirits.*

The reverend from the United Christ Ministry explained his understanding:

> *Evil spirits are unseen, but they are a common thing to attack a person. The evil spirits – we call them demons. It is written from the bible that there was a man full of demons, and those demons were taken away by Jesus. I can see that someone has been attacked if he is walking around aimlessly, roaming around, talking lonely, or too much talk and laughing without reason. That's how we see it. We treat it with prayer, a petition to God to help him. We can also treat with the casting – the hands on the head.*

The reverend explained that in addition to praying and counselling people with illnesses, they believe in the casting of hands by evangelists and pastors. This will cast away evil spirits causing the illnesses. In this practice they touch the ill person's head with their hands, as they believe everything comes from the head. The practice is part of a religious ceremony, as the overall aim is to connect the ill person to God:

> *I, myself as a reverend, don't have the power to do anything, but I offer myself to be used by God – he is the only one with the power. Everything I do is instructed by God, as stated in the bible.*

At the Presbyterian Church of Africa, they first and foremost refer the sick person to the doctor for help. Beyond that they pray for the person, or sometimes refer to the Zionists for exorcism. The leaders in this church are taken to a workshop to teach them how to deal with mental illness and social issues. They learn how to consult people, and how to recognise these problems:

> *As a leader, we must be prepared for any eventuality; some will appreciate help, some will not, but they still need help.*

I asked the church leaders what other places in Madwaleni, except for the church, they could think of that could be of assistance for people with mental illness. First and foremost, they

mentioned the hospital and clinics, but they also spoke about *izangoma*, especially in relation to mental illnesses caused by spirits or demons:

> *There is no conflict between us and them; we all want people to be healed. As long as we save people, that is the goal.*

5.4 Public health care services in Madwaleni

During my field visits to Madwaleni I visited most of the public health facilities (primary health care clinics, health centre and secondary hospital), and interviewed numerous health workers and users of the public health care system. I spoke to various kinds of health workers, both trained and untrained, such as, community health workers (volunteers), care givers, enrolled nurses, professional nurses, occupational therapists, physiotherapists, medical doctors and a psychology intern. All of these were providers from the many health programmes and departments at the hospital and clinics, such as Home Based Care (HBC), Orphans and Vulnerable Children (OVC), Community Health Worker (CHW) programme, Outpatient Department (OPD), General Ward and hospital management. I also interviewed a few representatives from The Donald Woods Foundation (DWF)[7] based in Madwaleni. Interviews with local chiefs also illuminated issues related to access to public health services in Madwaleni, and several of the chiefs are on the hospital board. This section, describing the public health services in Madwaleni, is based on information, experiences and views given to me in interviews with all the above mentioned participants.

5.4.1 General services at the hospital, clinics and health centre

One of the local chiefs told the story of how Madwaleni Hospital in its early days was intertwined with the Dutch Reformed Church. The missionary who founded the church requested of the then chief of the district for the establishment of a clinic, and it went on to be the hospital. This was in the mid-1950s. The hospital only became a government district hospital in the 1990s. The chief said that advocacy efforts of the chief and his older brother were crucial for the amaBomvana people to accept the invitation to use the hospital. Furthermore, the transition of the population into accepting the services has been historically supported by the traditional healers. Prior to this transition it was common only to seek traditional healer's counsel as it was the only option available. Post 1990, as a result of the implementation of primary health care, eight feeder-clinics/health centres have been built around Madwaleni hospital. These are spread around in the hospital catchment area, and one of the chiefs said that three of the locations were determined by the chiefs, while the remaining five were decided by the

[7] http://www.donaldwoodsfoundation.org/

government. One of the chiefs said that there had been an on-going disagreement between the local chiefs and the government as to the placement of the clinics.

Today the area is serviced by a hospital, seven primary health care clinics (clinics) and one health centre (HC); Madwaleni (hospital), Hobeni, Nkanya, Bomvana, Molitafa, Soga, Vukukhanye, Mkhatazo and Xhora (HC). Most of these are located between the two major rivers, except for Xhora and Mqele that are located outside of the Xhora River (see Figure 7 below).

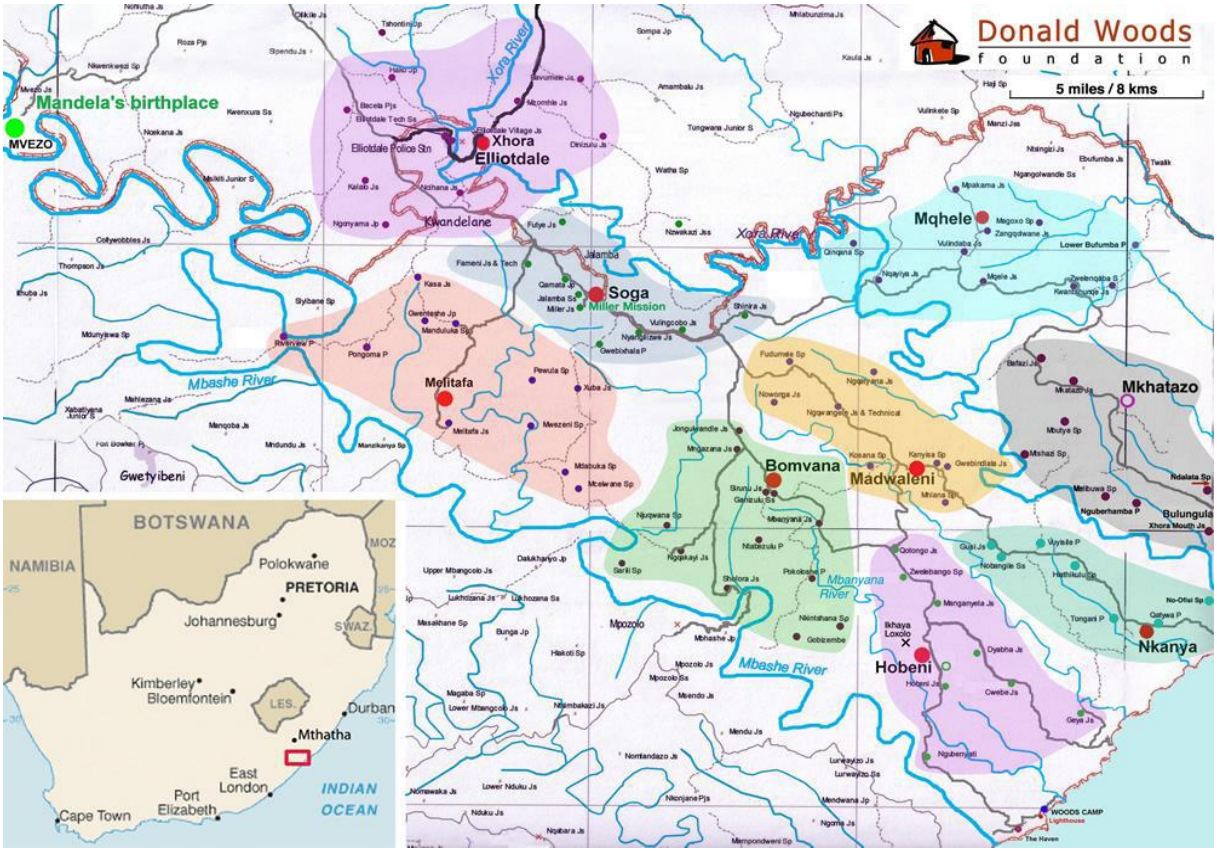


Figure 7. Map of Madwaleni Hospital catchment area

Madwaleni Hospital has 180 beds in seven wards, an outpatients' department and a dedicated HIV wellness and ARV unit. The first port of call for public health care in Madwaleni is the seven clinics and one HC. I was told that they have free clinic choice, so people can go to whichever clinic/HC they prefer, whether they live within the catchment area or not. The perception is that most people use the clinic closest to them, which is usually the one they "belong to". Due to the geographical layout of the area and the terrain, as described in Chapter 5.3.2, some of the clinics become unavailable to some parts of the community for large parts of the year. A local chief also pointed out that the clinics are not strategically placed in the community, but rather next to roads, and this means that people in the hills and valleys are often not able to access them. He told the story of a community member who drowned trying

to cross a river on his way to the local clinic. The chief feels that clinics should be embedded in the local communities.

The clinics and the HC experience poor water supply and lack of electricity, especially in the evenings and at night. The clinics are nurse-run, staffed primarily by nurses (professional and enrolled), assistants (cleaners/security/care givers) and community health workers (CHWs). They are severely under-staffed, and those who work there explained that they are extremely overworked, and work under difficult working conditions with long working hours, seeing many patients per day and hence have very little time with each patient. Most of the staff at the clinics and HC are isiXhosa-speaking, and members of the Madwaleni community. Because the clinics and HC were all built over the past two decades the buildings are in good condition. The staff, however, complained of shortage of equipment and medication in addition to the shortage of staff. The clinics are open between 8:00 and 17:00 (+/-). Emergencies outside these times should be taken to Madwaleni Hospital or to the HC. At some clinics, however, nurse's homes are located inside the clinic's premises, and many of the nurses living on the premises are willing to tend to emergencies outside the opening hours. This is a volunteer service they offer, as they will not be paid overtime. While a few CHWs may be working at the clinics, most of them work in the communities and visit people's homes. They do health promotion and prevention, and they also follow up on patients who need extra care; they give care advice and sometimes treat minor ailments such as sores. I was told that they are not allowed by law to carry and give out medication of any sort. Some CHWs have no training, others have some. The importance of the CHWs was emphasised by one of the local chiefs, particularly in early diagnosis and screening of illnesses. The CHWs are referred to as “volunteers”, but I was told that they do receive a small stipend (+/- R1000 per month) as compensation for the work that they do. Most of the clinics and the HC have posts for care givers, which are often CHWs who have been promoted to a paid post inside the clinic.

The one health centre in the area is located close to the only town, Elliotdale. The HC is open 24 hours and while it is better staffed than the clinics, it also suffers from staff shortages. The nurse in charge explained that they have status as a HC, they work like a HC, but they do not function as one structurally because there is not enough staff and they lack the funding for this. The HC tend to emergencies, and they have an operating theatre which is not in use due to lack of staff. While the HC is both a primary and secondary health service, they refer many patients to Madwaleni hospital that could have been seen at the HC had it been operating to its full capacity.

Lack of vehicles and ambulance services at the hospital, clinics and HC are limiting the transportation of patients to/between clinics/HC and hospital. This also prevents staff from

providing outreach services, such as mobile clinics, home based care, health promotion and prevention campaigns, etc. But, even where transport is available the bad quality of the roads, exacerbated by flooding and heavy rainfall parts of the year, was said to be limiting the health providers from getting to the communities. As a result, outreach to the communities and home based care services are primarily restricted to the CHWs, who work in the area where they live, as they are dependent on carrying out their duties by foot. To see a trained health professional patients mostly have to travel to the clinics or the hospital. The local chiefs emphasised this lack of outreach as a major barrier to effective health promotion, prevention and treatment in the area. Mobile clinics and other outreach services were more common in the past, but these services had deteriorated over the past decade or so:

> *There was a mobile health unit which used to visit the villages in the community and it meant that services reached the community rather than the community making the long trek (journey) to the hospitals. These visits also facilitated health promotion and since the stoppage of this aspect of the hospitals work the issue of transportation has compounded the health of the amaBomvanas and a deterioration of health promotion activities.*

The hospital has offered some outreach services at the local clinics in the period I have been visiting Madwaleni. In some periods these services have been consistent every week or month, sometimes more sporadically, and sometimes not at all. Examples of such services are rehabilitation, occupational therapy, TB and HIV support groups. Doctors' outreach has been in the planning for many years, but due to the shortage of doctors this has not been possible to implement. Orphans and Vulnerable Children (OVC) and Home Based Care (HBC) programmes have been running at the clinics, operated by the hospital, consistently for about five to seven years. This is mainly thanks to the on-going support and financial assistance from the Donald Woods Foundation.

Like the clinics, the hospital also suffers from severe staff shortage and also from rapid staff turn-over. This is most likely due to the fact that while many of the nurses at the hospital are isiXhosa-speaking and members of the Madwaleni community, most of the higher level health professionals are not. A local chief explained:

> *Staffing is a key issue in service delivery to the people of Madwaleni. The doctors are all White and the nursing staffers mostly amaBomvanas. There has been an attempt with doctors from Nigeria and other Black population but given that they prefer to operate private clinics their stay is limited. The other issue around staffing is crime; staff housing being targeted by thieves has resulted in doctors not completing their posting.*

> *The issue of thieving is compounded by the fact that there is no electricity in the surrounding villages so that they can know the movement of people overnight.*

Furthermore, several health providers complain about salaries and allowances not coming through on time, taking several months to come through. As one physiotherapist (PT) put it:

> *. . .which is very sad, because I know people that would come to this hospital, but because of the issues of finance and how long it takes, they are not willing to leave their jobs, and then come here and not get paid.*

One of the chiefs pointed out that the transient nature of key staff, such as doctors, means that very little of the history of the community, its health challenges and determinants of these challenges are retained for the best use of the amaBomvanas.

Over the past five years the hospital has experienced numerous periods of several months at a time without a single medical doctor and no qualified hospital management in place. A medical doctor at the hospital spoke of the problems of health care delivery in the context of such staff shortage:

> *We don't have the staff to allow us to be proactive about solving community problems; finding these community health diagnosis and putting a plan in place. We rather have to be reactive and downstream to the problems walking in the door.*

I was told that rehabilitation and occupational therapy (OT) services were introduced at Madwaleni hospital in 2007. Since then the hospital has had a consistent supply of community service OTs and PTs, and for the most part at least one regular PT and OT employed full time. These health workers are for the most part not isiXhosa-speaking, and not from Madwaleni, and hence the sustainability of these health workers is poor. A group of OTs told me that staff turnover is high among OTs and PTs, and staff handing-over and carry-over is not good.

The Orphans and Vulnerable Children (OVC) programme is funded by the DWF, managed by the hospital and run at the seven local clinics and the HC. The overall aim of the programme is making access to health care and social support as easy as possible to ensure that OVCs are cared for as best as possible in the community. Chiefs and headmen in the local communities identify a number of women and men as volunteers as OVC supporters. It is important to the success of the programme that OVC supporters are referred outside of their community as seldom as possible, to ensure that their services are accessible to the children concerned. The supporters are trained in OVC over a three-month period, and are thereafter allocated certain of the children to support through on-going home visits, where they assist with housework, school work, psychosocial support and more. The OVC programme identifies

orphans and vulnerable children (for example orphans, children with disabilities and children of parents with disabilities) in the communities through, for instance, chiefs, local schools, churches and local clinics. The children are brought in to the OVC programme where their basic health (immunizations, HIV, disability, all children are dewormed, TB, hospital referrals) and social (school dropouts, grants, care for the child through care giver at home, other social problems) needs are identified and they are assisted to meet these needs.

The Home Based Care (HBC) programme is also funded by the DWF, managed by the hospital and run through the local clinics. The programme was initiated to reduce average length of stay at the hospital. Before the programme was initiated there was very limited follow-up in the community, but with the HBC programme they now have what they call "beds in the community". The main aim of the programme is to look after people who have been discharged from the hospital (chronic patients, palliative treatment, patients who do not adhere to treatment), but people can also be referred to HBC through their local clinic or through people in their community. CHWs follow them up and visit them at home. The frequency of the visits depends on the condition of the patient, but most patients are visited every week. Each CHW is responsible for the area where they live. The programme is working with CHWs who are already at the clinic. The CHWs are separate from the HBC programme, they are working at the clinics, and belong to the clinics, and many were there before HBC started, and will continue irrespective of the programme. The HBC programme is working with all seven clinics and the one HC in the area. The nurse running the programme said that she thinks that one of the greatest challenges for the HBC programme is that many of the CHW have never been trained. She, herself, has been running training programmes for them since 2007. The main components of the HBC training are: Diabetes, hypertension and pressure sores (preventive, treatment and dressings). She also tries to provide training and counselling according to the problems and patients the CHWs encounter. The CHWs have weekly meetings at their local clinics, and that is a chance for them to ask for advice from the nurses at the clinic or the nurse in charge of HBC.

Many of the health providers spoke of the lack of collaboration between the different health programmes, departments and providers in Madwaleni. Several reasons were mentioned for this, mostly related to the lack of capacity among the limited staff that is available in the area. Furthermore, it was said that the hospital and the clinics/HC fall under different health departments and municipalities, making it more difficult for them to collaborate. One nurse said that:

> *There is that feeling that we don't belong together.*

Adding to this, the lack of a central data system makes collaboration difficult. As one nurse said:

> *As it is now, each part of the health care only know of and focusses on their bit of the treatment, and knows nothing of what has happened before, in other parts of the health system, and so the continuity of care is not good. Patient information is only in their health books, which patients keep themselves. If they don't have this, the health personnel know nothing of previous care and treatment.*

Despite the gaps and shortages in public health care delivery talked about by the health providers, few of them had experienced health care users complaining about the care that they get. Some of the providers felt that this says less about the patients' satisfaction, and more about their lack of awareness of their patients' rights and human rights. As one medical doctor put it:

> *. . . I'm not sure the majority of the clientele (at the hospital) are aware of their rights and of the possibilities and potential that they have. And if they were, they would be much greater advocates of what we are trying to achieve, and there would be much better quality control because they would be. . .pushing for us to be doing better. That's something that we really need, but we are not getting that.*

The health providers said that while there is widespread use of the clinics, HC and hospital in Madwaleni, many people in the community also go to traditional healers of various kinds. Some come to the clinic after bad or unsuccessful treatment there. They said that the reason people go to traditional healers is because of their cultural beliefs. It is common to use traditional healing for epilepsy, for example, but the view of most health providers was that it does not help. One hospital nurse, however, said that:

> *I would like to give my praise to primary health care. When I came to work at the hospital in (the eighties) people associated every illness with witchcraft. Now they understand much more. So health education is working well. Now there are few healers and sangomas in the area, and even those refer patients that are beyond their scope to the clinic and hospital. Some people believe mentally ill patients are struck by lightning or hit by witchcraft, but few sangomas treat mental illness.*

The health providers at the clinics said that they do not collaborate with the traditional healers, but many have told patients that it is acceptable for them to use traditional healers, as long as they also comply with the clinic's treatment. Management at the hospital told me that there are traditional healers represented on the hospital board.

The perception of most of the health providers is that family and community support systems are good in Madwaleni. Their experience is that most patients are well cared for at home, and get good assistance from family if they need help seeking health care. One nurse said that:

> *Many people have a very good support system at home. If you look at people waiting at the hospital most of them are not ill, they are just there as support for an ill person.*

The experience of a foreign PT who had worked in Madwaleni for a few years was that most families genuinely want to help the patient who is their family member:

> *A lot of patients have a good support system because of the family. . . . You'll find that they come with their children to the hospital, willing to learn, and they'll do an educational session to support them and make sure that they do the necessary stuff at home. . . . I think it's the culture; they are quite close, so the support system is really good. Me, personally, I have never seen any disrespect towards someone who is disabled. But we do hear stories of children being abused because they are intellectually impaired, and they don't understand. We have heard of stories like that, but personally I haven't experienced it.*

In addition to the positive aspects of family support, some health providers also spoke of supportive and positive attitudes towards disability in the Madwaleni. One of the medical doctors (a White man) at the hospital said:

> *The causative factors. . .well, the causative factors are numerous; from lack of education to poverty, to those environmental factors such as the topography that we live in in terms of their ability to cope with a particular disability. You know, to cultural aspects of one's acceptance of disability, which I must say, in this community I have been very pleased with. . . . I don't think people are judged very much compared to my culture. Mental impairment, for example, and hydrocephalus; you know, you'll see a child with hydrocephalus who is really quite difficult to look at and to think of as being a beautiful human being, but in this setting people tend to be quite accepting. And I don't know whether that's a resignation or an acceptance so much, but I'd like to think it's more the latter.*

According to the health providers, major health problems in the area are HIV and TB. Epilepsy is also a widespread problem, and I was told that the high prevalence of epilepsy could have to do with worms people can get from eating bad pig meat. The worms can result in neurocysticercosis (NCC), which again can lead to epilepsy. People who have epilepsy have to go to their local clinics once a month to pick up their medicine, and they have to go to the hospital every six months to see a doctor to get the prescription for their medicine renewed.

The condition and symptoms of epilepsy are charged with cultural beliefs. Alcohol use was also said to be an increasing problem in the area, especially among men. There are no treatment programmes for alcoholism; the nearest Alcoholics Anonymous (AA) is in Mthatha.

5.4.2 Treatment for mental disorders

When asked about people with disabilities, health providers generally talked about people with physical disabilities, to some extent people with sensory impairment, rarely people with intellectual impairment, but never people with psychosocial disability. Disability is broadly understood by the health workers as “inability”; “*people who cannot do what other people can do”* (Nurse). Many of the health workers had some experiences and thoughts about people with “mental illness”, but mental illness was not understood in connection with disability. I was told that mental health is incorporated into primary health care, and the health providers explained that the most commonly seen mental illness at the hospital and at the clinics is acute psychosis, often in young men, usually linked to alcohol and drug use. I was told that diagnosis is difficult:

> *They say psychosis, but it could be any mental illness. Psychosis is not a straight diagnosis, just an umbrella term for many mental illnesses.* (General ward nurse)

When asked about disorders such as depression, bipolar disorder and schizophrenia, they said that they rarely diagnose or treat people with these disorders. A nurse explained that patients with, for example, depression are rarely picked up for depression, but may be treated more symptomatically for sleeplessness, lack of appetite, and so on:

> *We don't treat them; we just cure the symptoms.*

The same nurse also explained that schizophrenia will usually be treated only when it is extremely severe. Very few patients come to the health service saying they are depressed or have anxiety. Those that do are the more educated people such as nurses and teachers. All of the health providers felt that health services for people with mental illnesses in Madwaleni are very limited, there is no one at the hospital or at the clinics with the overall responsibility for the treatment of mental illness, and hence most mentally ill people are never correctly assessed by the public health care system. One nurse explained that mental disorder is not seen as an illness by the health department, and therefore treatment is not prioritised. Her feeling is that mental health is nobody's responsibility, and is ignored by most health providers:

> *No one bothers about the confused people.*

She feels that awareness about mental health issues should be raised among nurses and community health workers, as doctors will attend to whoever is referred to them, so they are not to be blamed for the lack of attention paid to people with mental illness.

While the organogram of the hospital includes several mental health professionals, at the time of the three data collections there were no social workers, no psychologists, no psychiatrists and no psychiatric nurses at the hospital, nor at the clinics and the HC. The hospital has had short-term visits by psychologists in the past, but I was told that they usually do not stay long, and have had very little sustainable impact. There are no dedicated professionals at the clinic or the hospital to diagnose mental disorders. The professional nurses and doctors have some basic mental health training as part of their overall degree, but none of them have practised focussed mental health care to any great extent, if at all.

When people experience mental problems and decide to seek health care for this, firstly they have to visit their local clinic. At the clinic they will not find any mental health professionals, very limited skills among general health professionals in recognising or diagnosing mental illness, and lack of appropriate medication. A registered nurse working at one of the clinics explained that in the catchment area for the clinic she knew of four patients with mental illness. These patients had been diagnosed at the hospital, and sent back to the clinic for follow-up. She said that the hospital had packed their medication for six months, and this was to be distributed monthly from the clinic. If they see psychotic patients at the clinic they will sedate them and refer them to the hospital. For patients with depression she explained that they had guidelines to follow. These patients are to be put on anti-depressants, they have one default type they can give out from the clinic, and the clinic is responsible for monitoring and reviewing patients on such medication. If the patient does not get better, he or she will be referred to the hospital.

At the hospital I was told that the patients with mental illness who come there invariably come because of violent or aggressive behaviour, and because they are viewed as a potential danger to themselves or to others. Some patients have been referred from the clinic, which is the first port of call, to the hospital, other patients come straight from the community to the hospital. These patients often come to the hospital in a very bad condition, escorted (sometimes by family, sometimes by police), tied up or held down. They come to OPD, and from there may be admitted to the general ward where they stay for a maximum of 72 hours for observation and treatment. In the general ward medical conditions are mixed, and psychiatric patients are admitted among other patients. If patients are in a violent mood, they may be referred directly to the tertiary hospital in Mthatha, as the layout of the general ward is not suitable for violent or aggressive patients with mental disorders. People are afraid of them, and they can pose a

danger to other patients. In the general ward they will most likely be treated with sedatives or anti-psychotic medication. Relatives often stay with them, and they are encouraged to stay with them, because of the layout of the ward; with so many other patients around, and the staff not being able to stay with the psychotic patient at all times. The staff sit with the relatives and explain about the patient. Patients who were referred to the hospital via their local clinic will also be sent back home via their local clinics when they are discharged from the hospital, so they can be followed up by the clinic. Other patients are sent straight home, not via the clinic. If they are not behaviourally more settled after 72 hours at Madwaleni hospital, they will be referred to Mthatha General Hospital, which is a two-hour drive away. If a patient is referred to Mthatha he or she will be taken there by an ambulance sent from Mthatha to pick up patients from Madwaleni. A nurse in the general ward told me that over the past four months they had only seen two patients with mental illness, and a patient with depression they had not seen for over a year. I was told that at Mthatha they have a psychiatric specialist, but not a psychiatric ward. I made an attempt at interviewing someone working in psychiatry at Mthatha general Hospital, but they were reluctant to talk to me without permission from the hospital management. In the period of time that I was there I was not able to obtain such permission, and hence was not able to carry out this interview.

Some years back, in about 1995, there was a psychiatric clinic at Madwaleni hospital. This clinic had just one psychiatric nurse who provided counselling, medication and referral for psychiatric patients. He prepared packages of medication that were sent to the patients' local clinics, where they could collect it and be followed up on a monthly basis. Patients would still have to come to the hospital for review, but only once or twice a year. The nurse, who still works at the hospital but no longer with mental health, said that he used to see patients with epilepsy, psychosis, schizophrenia and substance abuse problems. This nurse also used to advise health providers at the hospital on management and treatment of psychiatric patients. He explained that the psychiatric clinic was closed because services for mental health were decentralised, and responsibility put on the clinics:

> *The situation today is that mental health is one of the sectors that is being neglected by the department. Nothing is being done. The nurses at the clinics lack the knowledge to diagnose and treat mental illness, and patients don't trust the treatment system, so they don't come for treatment.* (Psychiatric nurse, used to run psych clinic)

Another nurse at the hospital said that the psychiatric clinic was closed because of the scarcity of psychiatric patients coming to the clinics and hospital, and it was felt that this nurse was not utilised well enough:

> *This has left a big gap as far as psychiatric patients are concerned at the hospital. It is a problem that no one works with psychiatric patients only, so no one has time to become really good at it, and practice that side of the job only. Even I, who have some training in mental health; I forget a lot when I do not practice it.* (General ward nurse)

Towards the end of my last fieldwork trip in 2012 two intern psychological counsellors from Walter Sisulu University in Mthatha arrived at Madwaleni Hospital. They were both isiXhosa-speaking, but not from Madwaleni. The intern I spoke to explained that while he speaks the language, the dialect spoken in Madwaleni and his dialect are very different. Similarly, the Xhosa culture he comes from is very different from the culture in Madwaleni. The interns, the first of their kind in Madwaleni, were in their fourth year of a degree in psychological counselling. They were due to stay for six months, after which period two new interns were due to take over. They had no qualified supervision at the hospital; their supervisor was in Mthatha, and they travelled there once or twice a month to meet with her. In my interview with one of the interns he expressed concern about this lack of supervision:

> *There is no one above us at the hospital, and we might do something that we shouldn't do, because there is no one to tell us what we should and shouldn't do.*

In the short period of time he had been at the hospital he had done some VCT-, trauma- and grief/bereavement counselling. He was dependent on other health workers referring patients to him. They were also planning to visit the clinics to talk to the health workers there about mental illness and referral, and to give other health workers tips for counselling. The intern felt that as far as mental health care is concerned, the main problem is with the people:

> *People here don't believe much in talking. They need to be convinced to talk, and of the benefits of talking. Some are convinced and do see the benefits, others will not talk. When there is a problem they do the cultural thing, related to witchcraft, and they take it to the traditional healer who gives herbs, but they never work. So they only come here (hospital) when they are severely ill.*

The OT department at Madwaleni hospital are sometimes involved with the care of psychiatric patients who are admitted to the general ward. Their role is to deal with the family's handling of the situation; to advise them on how to care for the patient, for instance making sure the patient has a full time carer, give advice on medication and assist them to get a disability grant. One of the biggest challenges they face are related to language, as none of the OT's are isiXhosa-speaking, and very few patients can communicate in English. Generally, they will use a nurse for interpretation:

Most of the nurses have no, or very limited training, in mental health. Often the messages from us (OTs) to the patient get lost in translation. Also, people often associate symptoms of mental illness with witchcraft, and this makes patients, as well as the translating nurses, very scared and uncomfortable.

5.5 Traditional healing in Madwaleni

During my fieldwork I was introduced to five different traditional healers living and working in Madwaleni, all but one had been born and raised in Madwaleni. The collective term used for the healers, in English, was "traditional healer". Other terms I have come across to describe these healers are *"sangoma"* (plural: *izangoma*) (Zulu term), *"amagqira"* (isiXhosa term), “prophet” (sometimes rendered as *"umprofita"* (singular) and *"amaprofita"* (plural) in isiXhosa) and "faith healer". As terminology and variations in traditional healing is not a focus point of this project, I have not explored in more detail English and isiXhosa terms for traditional healers. The healing practices described here do not do justice to the variety of traditional healing practices available in Madwaleni. It is outside the scope of this dissertation to explore the range and depth of Xhosa traditional healing, but rather to explore the pluralistic nature of care available in this context.

The main focus of this section, describing traditional healing practices found in Madwaleni, is to describe traditional healing related to psychosocial disability. I will, however, give a description of the different healers and their healing practice before I go into more depth on their perspectives of psychosocial disability and their approach to caring for these particular patients.

5.5.1 The traditional healers and their practices

The first healer I was introduced to was a faith healer from St. John's Church (Healer SJC), a man in his fifties. The basis for his healing practice is holy/spiritual water, with which he cures people who are ill because of bewitchment. This water is normal water, but it has been prayed for by healers from SJC. There are many such healers in South Africa, and the healers in the Eastern Cape get their water from "the source" in Mthatha, which is a bishop from the church. The bishop in Mthatha gets the water from a bishop in Lesotho, and he is the "top leader". At all levels the water is prayed for, and that is why this water has special healing effects. He became a healer after he himself was sick, and he got well after seeking help from the spiritual healer in Mthatha. The spiritual healer in Mthatha saw in him that he could be a leader and asked him to take the water to Madwaleni and heal other people. This quality to be a healer, and the ability to eradicate witchcraft, is something one is born with. In his practice the prayed for water is mixed with regular water and this mix is used in the healing. Patients drink the

water, bathe in the water, vomit the water or get sprayed with the water. He has a small clinic and rooms for seriously ill patients to sleep overnight, and he has a bath on his property, which is where the patients bathe in the holy water. The bath is aimed especially for eradicating witchcraft, as it washes it away. After patients have been treated at his house, they have to continue taking the water, as he explains that if they stop taking the water their protection from witchcraft goes away, and they can be bewitched again. Patients often use his treatment in combination with hospital treatment, and he often encourages people to use hospital treatment in addition to his. There is no formal collaboration. He said that the difference between his treatment and the hospital is that he does not use medication or pills, just water.

> *I have seen the difference; water heals many people, more than the hospital. When people drink the prayed for water they feel the difference from normal water; it helps much more. It's the prayer that makes the water so different from other water.*

The second healer I met was an elderly man referred to as a prophet. The basis for his treatment is partly communication with ancestors and partly communication with God. He belongs to the Free Glory Apostolic Church in Zion. The prophet got his calling when he was in his fifties, and he had been a prophet for more than 20 years when I met him. He explained to me that it is predetermined who gets the calling, it is not something anyone can choose, and to become a prophet one has to have a calling. The calling happens in the form of ancestors communicating with you, telling you to become a prophet. When he got his calling, at night while he was asleep, he said it felt like dreaming, and he became sick. Only when he did as instructed by the ancestors did he become well again. The ancestors instructed him to make some offerings in order for him to get connected to them. They also instructed him to take certain herbs to make his visions clear and for him to be brilliant. Finally, he was instructed on what herbs to use in treatments of patients, where to find them and what the different herbs are for:

> *I am a prophet, the link between ancestors and the community.*

When a patient comes to him he starts by sniffing him for about fifteen minutes:

> *The sniff goes through the nerves, and the tears come down. When tears come down that person gets better. I can do this if a person has been stolen by being bewitched. Then I must wash him with herbs.*

But it is crucial in his treatment that God is also part of the healing:

> *"In the name of the son, the father and the holy spirit". . . If God is not part, healing cannot happen! Ancestors, while people are dead; they are still alive. Ancestors, God*

> *and living people are still connected. You can do nothing if you don't pray and don't talk to the ancestors. One must obey God and also obey the ancestors – it's a 50/50 divide.*

He does not work together with the hospital, but sometimes if a patient needs the technology that is only available at the hospital, like a drip or an X-ray, he tells them to go to the hospital. Some illnesses, he says, can only be treated by the traditional healer:

> *For example, HIV; you can got to clinic, to VCT test, but they don't see it. After a long time, they will see it when it has already beaten you down. I can see you and see the illness, and give you herbs, and you'll be right. I am not in favour of doctors; they give answers and help in very last moment, when they SHOULD treat very early. In South Africa; count how many people are dead by HIV, the question must be WHY? There is no limit of the death. Everyone is dying, it's gotten worse. I don't care about the hospital; it's a waste of time, I prefer to treat them here.*

He often dreams of people who are sick, and how to heal them, but he cannot help them before they come to him. He said that he can treat all illnesses, but treatment becomes difficult if the person comes to him too late; after having been sick for a long time, when they are "already finished by the illness." But if the illness is "new", he said, he can treat it easily.

The third healer I met was a young man and a Zion prophet similar to the second healer. He got his calling in 2009, while he was asleep. A few days prior to the calling he had started to lose his sight. He believes that losing his sight was part of the calling, as his sight came back as soon as he gave into the calling and followed the instructions from the ancestors:

> *The ancestors then told me I must take some kind of herbs. So I took the herbs, drank them and bathed in them, and I started to see again. This started by a dream for the first time, but I think it has been transferred to me by genes. I think it started when I got blind; it was part of the call. It took only one day from the blindness to the actual call. My grandfather and father's young brother were like me; they had the call. My grandfather passed away before I was born, and my uncle could not continue with his call. They never taught me anything. So ancestors took the call from them and gave it to me, and they (ancestors) taught me.*

The link between the Zion Church and him being a prophet was given to him by the ancestors. He was never a member of the church before he got his calling, but the ancestors told him to become a leader and a prophet in the Zion church:

> *The ancestors didn't allow me to practise sangoma activities, they drove me to become a Zion prophet. The ancestors decided, not me. My grandfather and uncle were*

> *sangomas, but they were not Zion prophets. The focus of the Zion church is that we heal people, and we assist people with calls by ancestors. We pray to cast away bad spirits and diseases, and teach people this practice. Someone with problems they can be assisted by practicing prophet system.*

He heals people in his home, and heals people from all churches, and even non-religious people. He said that non-believers get healed only through the help of ancestors, as they have to believe in God to be healed through God. In the healing he uses herbs, and he gets help from God and the ancestors to determine exactly how to cure and treat people:

> *For example, I sleep at my home, and while I am asleep someone that I don't know is dreaming of me assisting him with sickness, and I also dream of this person, and his sickness. This person has to come to me for help after he has dreamt of me. Sometimes I know the person, sometimes it is a stranger. I have to get a message from ancestors on how to heal. It happens by both parties; both the ancestors and God. God sends a holy spirit to open for me and tell me, and then ancestors can come and tell me what to do. These work together. I don't call them, they are always with me; anywhere I am they are there, and they can stop me or guide me in what I do.*

He explained that there are some illnesses that he cannot treat, and if he sees people with these illnesses, he will refer them to the hospital. People with mental illness, for instance, he cannot treat. Furthermore, he explained that there are certain things that cannot be diagnosed and treated by the hospital:

> *Some people come to me, and when I am prophesying them I can see the poison, while doctors will see for example TB. Our interpretation is different – in the way of diagnosing we differ. While I can see a person has been bewitched by using poison, the doctors cannot see that. This is a tricky thing, because when people practice witchcraft, they prevent the doctors from seeing it. They want that sickness to eat you. If you have been bewitched, modern medicine cannot help you. Witchcraft can cause any illness. I assist people by mixing some herbs that people clean themselves with, drink or cover themselves with.*

He told me that not everybody can bewitch others, but for those who can bewitch, jealousy is a major cause for bewitchment:

> *Say, for example, wealth; a young guy shepherding a flock belonging to his mom and dad. The family has too much wealth, and the boy will become rich soon. This makes people jealous of him, and they bewitch him. God does not give you wealth while you are jealous, so while you are jealous and bewitching, God denies you access to wealth.*

The fourth (chief *sangoma*) and ***the fifth*** healer (woman) I spoke to work together. The fourth healer, a man, is a chief *sangoma* of a traditional healing practice consisting of a "training hospital" in the Madwaleni community, and a "dispensary" (medical outlet) in Elliotdale. The fifth healer was a woman who had been trained by the fourth healer and worked for him at his hospital. Hence, these two healers practice the same kind of healing and share the same beliefs. Similar to the other traditional healers I spoke to, the fourth and the fifth healer also explained that to become a healer one has to have a calling. They had both had their callings through a dream, accompanied by illnesses that were only cured when they gave in to the calling. The woman told me that she had been blind for almost six months, and that the blindness went away when she started listening to the ancestors who were telling her to go into training to become a traditional healer. The chief *sangoma* trains many traditional healers. The main components of the training are how to use what they refer to as herbs and how to communicate with one's ancestors. The training has ten levels, and a trainee completes one level at a time. To complete all ten levels takes years. They compared it to university training, where one completes a bachelor's degree, honours, masters and PhD. They can practice as healers even if they have not completed all the levels. When they are qualified to start practicing they get issued a certificate from the South African Traditional Healers Association, and they say that to be able to practice as a healer one has to have that certificate. The key elements to their healing practice are communication with ancestors and the use of herbs as instructed by the ancestors. What they refer to as herbs can be anything from bark of trees, roots, leafs, flowers, herbal plants, animal fats, animal skin, bones and so on. It is the ancestors that tell them, for each patient, which herb to use and how to use it in the treatment of that particular patient. The ancestors, they said, are messengers of God, the link between living people and God. Hence, they see God as essential to their healing practice. They explained that everyone's ancestors are different; they are deceased family members. But people's ancestors can communicate, and the female healer gave an example of this from their healing practice:

> *If this lady is coming to me (for treatment) her ancestors are talking to her. Now, if she is coming to me tomorrow. . .at night my ancestors are telling me: "Tomorrow another lady is coming to you!" Because that one's (the lady's) ancestors are connected to mine. If I am going to examine somebody who is coming, you can see him or her during the night when you are dreaming of somebody coming here with a problem. And the following day she comes, and you examine her, and you just tell her that thing you have been told by the ancestors when you were asleep. And the very important thing is to tell her or him, if you are telling him about his news, and in the end you tell him what was the reason for him to come here. He or she knows that you are telling him the*

exact thing, because you are telling him of things that have been done during your absence, you were not there when that happened.

They collaborate with the hospital through referrals, joint workshops and so on:

I do even have the reference letters to the hospital. But it's not every sangoma who have been chosen to refer people to hospital. But I have that agreement. We do have some workshops together with staff nurses and doctors at the hospital and clinics. We create that kind of link of common understanding of each other. For instance, there are those people who have been affected by HIV positiveness, and there is some specific treatment from the hospital which is different than our treatment. So we are being trained and told that we must do this and this, we treat this like this, but they don't deny our access to treat that person. There is a period given to us. Sometimes they can use both hospital treatment and our treatment.

5.5.2 Perceptions of mental illness

The ***first healer***, from SJC, explained that people who come to him for treatment with mental illness or any other illness have been bewitched. According to him not all, but a lot of illness are caused by witchcraft. He explains that there are a lot of witches around, there is a whole congregation of them, but he does not know who they are. Witches can be both men and women. *"Amafufunyane"*, according to him, is a practice of witchcraft which can be done to someone while they are sleeping. The SJC healer explained that evil spirits (or witches) scratch or cut someone while they are sleeping. The cuts will not be visible to most people, just to healers, like himself:

When evil spirits cut you it does not show like now, but in time it goes and goes, and eventually it goes to your head and you can get ill and eventually crazy. But you cannot see it immediately. Jealousy can cause it; if you are doing well they do that to you, the evil spirits. If they see that in your house you are the breadwinner, and there's a lot of things that you are going to achieve. Not just anyone can do it, because there has to be a way you can enter that house without being seen. That someone is a witch, and one has to be born a witch.

The ***second healer***, when asked to explain what mental illness is, said:

As for mental health issues; there is stress caused by hypertension because of maybe heart problem, or as a result of problem in the heart. Stress, sugar diabetes and hypertension are similar things, but mental illness is different. I am not sure a person is born with a short mind. When a person is growing up, the mind is rebuilding, you notice

> *something is short in mind because of illness. It is affecting the nerves, like with stress and hypertension. This is when they need to use traditional herbs. First sign to notice is that a person who is always positive and perfect, but all of a sudden he does unusual things, like taking a stick and beating someone or something, forgetting things and misusing things.*

He said that there are several things that can cause mental illness, such as suffering, bewitchment and jealousy. As an example of suffering he spoke of someone coming from a rich family, and their parents die so they are left alone, their belongings are taken away, and as a result they become "mad, stressed, stroked and so on." Bewitchment can be because of jealousy, and jealousy is usually liked to someone who is doing well for themselves, such as:

> *If someone is not working, but he is still making money, getting dowry for daughters, and so on. Someone who is doing well without too much effort – others are often jealous of this person. Someone who is jealous of you may bewitch you. Anyone can bewitch because of jealousy. There is too much jealousy! This kind of bewitched is like when you drive your car, you can see a horse, but others cannot see it, but then you hit the horse, and you die. Others who have not been bewitched, they don't see the horse, and they don't die.*

The ***third healer***, when asked about mental illness, said:

> *A person with mental illness is short of thinking and a bit mad. Mental illness can come from being bewitched. I don't know how it happens.*

I asked him about his understanding of being happy, and he related this question to his patients; that they would be happy if he could help them with their illness, and unhappy if he was unable to help. His thoughts on depression were as follows:

> *People like those you can see is a quiet person by nature, if they are being depressed by things. We need to give them instruction to obey; comply with medication, like taking tablets. If they don't comply they won't get better. Like an example of two people; one is happy and one is becoming sad. I advise the one who is unhappy to move away from that mental place, to think of something else, to be assisted to feel better. Also; those laughing at those grieving and sad – it's not nice.*

The ***fourth*** and ***fifth healer*** told me that they had seen many patients with mental illness, and at the moment they had two such patients, both with epilepsy. The fifth healer explained how they see that someone is mentally ill and how someone can become mentally ill:

> *There is no kind of symptoms you can identify, rather than you just see that the patient is being brought already mad. If a person is mad there is no question, you just see that the person is mad! They were running away; you have to tie them up. It's serious. Starting by sometimes epilepsy and lack of treatment, so that kind of sickness goes up and affecting mind. And then some is becoming stressed, so it's becoming mad. Some was just intoxicated by the evil spirit, like zombies. (They are intoxicated) by those people, they are wizards. These people (wizards) are working during the night when people they can't see them. . . it's like magic, like magicians. Because they do things we cannot see, which you don't understand. And even if they are moving around you cannot see them. It's a person; it can be a person in the community that is a wizard. There are some people like that. It's like using miracles. Like, if at night you are being choked in a nightmare. So I say tomorrow; 'eish, I couldn't sleep last night. Why; I've been choked by the nightmare.' And it's where the wizards are starting their progress, or their job. They are starting by sending some nightmares. It's me (the healer) who is going to heal the person who is having a nightmare. After that nightmare you get tired, you are restless always, because tonight there was a nightmare. And it was squeezing you like anything, and you have to scream. When you are crying, you don't cry as usual, you just scream, because the nightmare is on top of you. Sometimes you are scared, you are always sacred, because you see something wrong there, but you can't see it with naked eyes. You can feel it, and you see the person, but you can't touch it.*

They explained that if someone is affected by such a nightmare through witchcraft they have to get treated, or they will change and become mentally affected. I asked them who these wizards are, and they said that they don't know. The wizards, or witches, are regular people from the community, but they can't see who is a witch, because they hide it, they have a hidden agenda.

In the Madwaleni community there are a lot of people who suffer from epilepsy and/or seizures, and I asked them if they knew why. The fourth healer explained that:

> *I guess the cause or the source of this epilepsy it can be different. Some can be bewitched through that kind of nightmare, and ended up with epilepsy. But some can be caused by stress which was caused by hunger. If we don't have enough food at my home and we don't know how to get and utilise where to get food, it becomes affecting my mind and it created stress now. And that kind of stress can create me to have epilepsy, heart attack and stroke. Or sometimes one has been beaten by stick on the head. So if that person is not bleeding, that kind of blood vessels can affected and*

stroking the nerves where the nerves is being shocked. Then the person can start epilepsy. Now your vain has got a clot now, and the blood can't flow through.

5.5.3 Treatment for mental illness

The ***first healer***, from SJC, treats people with mental illness with water, like with other illnesses, but they also stay with him for a week or two to be looked after. If the person is on medication from the hospital, he will not stop him from taking that medication.

The ***second healer*** explained that in treatment of mental illness he starts by sniffing (smelling) the patient to diagnose them and find out what treatment to use. He uses traditional herbs, and it is his ancestors, which he refers to as prophets, that tell him which herbs to use in the different treatments and for each patient:

As our tradition as a Black nation we believe in prophets. The prophets show me and tell me what kind of herbs to use to calm the situation. I have medicine for a person who is becoming mad. I use herbs, and also injection (herbs) to calm him down. It's not easy to heal a person, the life of the ill person is depending on me, so I must make sure that I do the right thing.

If someone is running away he connects with the ancestors to find out what is going on with this patient. He also explained that the treatment for mental illness depends on how it happened, for instance witchcraft due to jealousy and hatred, or suffering due to events in one's life.

Sometimes just the process of sniffing will help a person to become normal. Sometimes they also need to take herbs. But it is crucial that God is also part of the healing.

The treatment usually takes between one and two weeks, and mentally ill patients usually stay with him during this period.

Sometimes patients come to him thinking they are "mad":

I could see he is not mad, but need to be calmed and given direction. He might be called (by ancestors) – he is not mad, but he is being called, and he is not aware. I can see this, and I can help with the calling.

All his treatments for people with mental illness have been successful, and he said that is why he does not believe in the hospital; because he can treat the patients. Nobody comes back with problems after having been treated by him. But in order for someone to be healed they

have to comply with his treatment; they have to take the herbs, and they have to pray to God for the herbs to work. He, himself, as a prophet also has to pray for his treatment to work.

> *Talking and praying changes things to the positive. If you do things shutting your mouth, nothing will happen.*

The ***third healer*** had never treated a patient with mental illness, and explained that he would refer such patients to the hospital:

> *To these patients I don't give anything; I refer them to hospital. And if hospital can't help, they refer back to me. Since I have started as a prophet I have never treated a patient with mental illness, I have only referred them to hospital. One guy from the forest was sick with mental illness. I referred him to the hospital. He was acting strange; talking lonely, not focussing, using sign language. My ancestors told me not to touch that person. They stopped me, told me not to touch him, but I thought it would be better to refer him to the hospital. He never came back. I don't know what happened to him. This is the only mentally ill person I have helped with referral.*

The ***fourth*** and the ***fifth healer*** explained to me how they go about treating people with mental illnesses, especially those who have become ill due to a nightmare brought on by witchcraft:

> *You need to be healed to get out of that nightmare. You need to be healed with medicines. And not only medicines from the chemist, but the medicine that are herbs. Not English medicine. English medicine is nothing. And if you go to hospital, nightmares going there is going to kill you. Because there are English doctors; there is no chance there. Because they only use injection and tablets and English medicine. Nightmares . . .you can't chase it away with injection and the tablets. It has to be treated with herbs and fats. . .animal fats. It can be wild animal fats. Some of them we put them on your body. Some you put them in a fire, a small fire. And that smoke goes to that person. You take a blanket and you cover yourself. You inhale it. Some others you can eat and drink, but not all. And bones of animals. You grind bones to make herbs. To make medicines. Even the skin of animals; you can make herbs from it. And plants, bark. Even snake is a medicine. The skin of a snake; it's a medicine. My ancestors tell me how to mix herbs, what herbs to mix and how. It's different every time.*

5.6 Concluding statement

In this chapter I have given an introduction to and a general overview of the context of Madwaleni; the area, the people, health and healing practices, and other care structures. This chapter is the background to the case studies which will be presented in the next chapter.

Chapter Six: Results – Case studies

6.1 Chapter outline

This chapter is a presentation of six case studies. In each sub-section a case will be presented in a descriptive manner, including comments from two independent psychiatrists on their views of what psychiatric diagnosis each particular case may have. It is common in multiple case study research to present the cases intact one by one, as in this chapter. This will be followed by a cross-case analysis and discussion emphasising on the quintain in Chapter Seven. The primary data in the case studies are from the cases, but data has also been collected from other sources that shed light on the quintain (Stake, 2006).

6.2 The cases

Six different case studies will be presented in the order they are listed in Table 3 below.

Table 3.

Case study informants

The case studies (all names are pseudonyms) and year of interviews		
1	Khaya: Man with stress/stroke/mental illness	2012
2	Pumla: Old woman with mental illness – Interview with her son (Andile)	2011
3	Thamisle and Aseko: Married couple with mental illness and family problems	2011
4	Nomabali: Old woman with mental illness – Interview with great-granddaughter (Vuyelwa) and daughter-in-law (Sylvia)	2012
5	Smikite: Girl with depression and family issues	2012
6	Zoliswa: Woman with mental illness – interview with mother (Novusile)	2012
	Psychiatrists	
1	Female psychiatrist from Tygerberg Hospital in Cape Town (Psychiatrist 1)	2013
2	Male psychiatrist from Tygerberg Hospital in Cape Town (Psychiatrist 2)	2013

6.3 Khaya

Khaya was more than a "case" and an informant in this study; he was also my interpreter and an important part of the final, and most crucial, phase of my fieldwork for this PhD. Khaya was born and raised in Madwaleni, and he has lived there for most of his life. He knows the area,

the community and the people as a community member, as a volunteer health worker and as a preacher and later a reverend in his church. Khaya helped identify and recruit many of the informants for this study, and he was a crucial participant as well as an interpreter in many of the interviews. In addition to sharing his own story with me, he also assisted me throughout the fieldwork in understanding the culture and the context of Madwaleni. Having assisted me in several interviews with people with psychosocial disability, he one day asked me if he could share his story with me. He wanted to share his story because he felt that he himself had at one point in his life suffered from a mental illness. However, Khaya's story is more than a story of mental illness; it is the story of a man's life and the many events and experiences in his life resulting in episodes of mental illness. It is also a story of the choices he has made in coping with his illness. Conversations with Khaya were in English, and hence any quotes used in his story below are direct and verbatim quotes. He told his story to me primarily through one long conversation. Very few questions were asked by me, as he knew from interpreting several interviews for me what information I wanted. Some information about Khaya was also obtained through working together on a daily basis over a period of four weeks, during my last fieldwork trip in Madwaleni.

Khaya, a man in his mid-fifties, is a Christian. He was born into what he calls a "traditional" family, by which he meant that he was not born a Christian, but became religious later in life. He said that when he was in the forest with other young boys during initiation (part of the circumcision rituals) he realised that he did not want to go back to being the young boy he was before; drinking and being irresponsible. He decided to go to church instead. He introduced Christianity to his family. He was circumcised in 1978, and got married to his girlfriend four years later. Shortly after they got married they started trying to have children, but ten years later they still had no children, and Khaya decided that they had to seek help:

> *The problem was not in me, but when I went up and down to different doctors; traditional healers, sangomas and all of those people – they could find that the problem was in my wife.*

Having identified the problem and received help, his wife finally became pregnant and had a baby girl. Unfortunately, at only six months old the baby passed away. Shortly after the death his wife fell pregnant again, only to lose this baby as well:

> *In five months pregnant it was just off. Nobody know where was it, because there was no miscarriage, no nothing. So I suffer, I suffer, I suffer. I took her (his wife) to Butterworth* (140 kms away, 2 hrs driving)*, looking for another doctor, I went up to Kentani* (200 kms away, 2 hrs and 50 minutes driving) *looking for another traditional*

> *healer. She did help us. So after that first born baby passed away we got three pregnancies, but no one was successful.*

During this period, in the mid-to-late eighties, Khaya had left his home to get work in the mines in a town a few hours north of Madwaleni. His wife stayed behind at home. Khaya became involved in politics, with the African National Congress (ANC), leading up to the release of Nelson Mandela from prison. In 1987 he was fired from his job at the mines after a national mine strike, and around the same time he was jailed because of his involvement in politics, charged with causing public violence:

> *Some other guys there were found guilty and they were fined R1100 (approximately US$200 at the time). I was not fined, and I was repaid all my money back, and they give me my unemployment benefit fund. I took it. So I came back to my home, I stayed here with my wife. We stay, we stay, we stay, we stay, and then my wife decided to leave me while I was unemployed.*

His wife was working at Madwaleni hospital at this time. Khaya had secured her the job through his many connections in the community. When she started working at the hospital she had met her old boyfriend from school:

> *This was before we were divorced. That boyfriend caused the divorce. She met him again and she recalled that love. That started to stress me, because I was unemployed and my wife started to divorce me. So I was lonely. That hurt me. Really. Because I lost my energy by trying to have good health for her. I was busy because I was loving her. So I offer all my time and my effort trying to assist, handling her. But my wife couldn't accept it, didn't appreciate it.*

His wife sought help from her sister in the divorce process:

> *So those sisters interfere in our love, by trying to have some suggestions. . .while I was not involved trying to talk about those things. Sometimes when you want to come up with suggestions you need to talk to those people both. If you want to interfere by giving some suggestions to married people, you need to be clever, taking them both if you have suggestion you see you want to try to rectify. You need to have a clever mind by calling them together coming to you, and you talk to them both. The sister failed to do that, she was always on her sister's side, accusing me of not caring for her sister. So I was so isolated. So I started becoming stressed because it hurt me.*

Khaya spoke of a particular incident that happened after the conflicts with his wife had started, but before they were divorced. The incident happened on a Thursday before a particularly busy

weekend for Khaya. Over the weekend he had promised to help with the ploughing of several gardens, he had also arranged for someone to come and thatch the roof of his home, and quite suddenly a woman and a man from the community had both passed away. He had been asked to be the preacher in both funerals, with ceremonies Friday, Saturday and Sunday over the same weekend. With quite a logistical challenge trying to fulfil all his commitments, Khaya asked his wife for help, but she refused saying she wanted to visit her mother who had been ill recently. Khaya felt angry and disappointed, but agreed for her to go:

> *In the afternoon (of the Thursday) I was standing here on the road with Vuyelwa (a neighbour), and we were talking about that funeral. I just realised something happening in my face. My face was starting to move this way, like. . . . I am starting fits, but it was not fits. I look to Vuyelwa, and she couldn't see what is happening, so I hide myself. Because I am avoiding that if there should be something noticed by her she will scream. So I don't want it, because she will be hurt while she see something is wrong in me. This was the time I was going that side to collect the tools and oxen to work that garden the next day. I just went back home. By the time my wife was already gone. By now my face was moving too much. I could feel it. Like something is holding me like this (pulling his face back), and something want to turn my neck. . . . My feelings, I was just like sober, I could feel it and it was like something shaking me. And I go down to the traditional healer that side. I just went down to him, and I got his wife, as he was that side looking for his sheep and cattle. The wife tried to assist me, she could see something was wrong with my face, but she couldn't assist me. She tried to call her husband, and she started screaming now. And I said, "No, don't scream, because you will call many people, and I don't want that because maybe it will cause a lot of problem. Let us wait for it, maybe we will just observe what will happen." So that traditional healer came and tried to give me some traditional medicine, just to see if sometimes. . . because the traditional healers sometimes they look after the devil spirit. Thinking of maybe it might be the devil spirit, so trying to use such medicine which fight that. It was just a medicine to drink, I don't know what is the name. So I tried to drink it, but it didn't help. So the traditional healer suggested that "let us go to the hospital, maybe the doctor will help." We came up to this shop here, asking this man who work here for his car to take us to the hospital. I don't have money, I was only having 40 rand in my pocket, and 20 rand I was supposed to pay that man who is thatching my roof, and 20 rand was just to stay at my home, for having some food. Now I was supposed to take both those 20 rand paying that man (to take me to Madwaleni), and that man say, "I want 60 rand, and if the 60 rand is not available, I don't go." So we just walked. And while we walked from here it became worse, because my mouth was like a fish when*

it is out from the sea, when it's burning by the sun. So my mouth was just opening like someone was opening it. I couldn't chew or eat like this, and I felt very, very, very pain. And then my ankles. . .I started to walk with my ankles now, my feet were so bent, so paralyzed, I had to walk on my ankles, the outside of my ankles. I couldn't walk, so I was supposed to walk. They wanted to carry me. It was my wife. . .because we called my wife back; she came. It was my wife, my brother's wife, myself and my brother. We walk up. We suffer. We go up, you see the red roof after the school, on top there? We went there on that red roof. This was about 8 or 9 in the evening. Then that man said "unfortunately my car's steering is loose", so he can't drive. The car can start and go, but is not turning. So we walk up across the river, and we get another man, and when we get that man awaken we pray and pray and pray, and he said, "give me 20 rand, I want to just add my petrol, and then I take you to Madwaleni. The rest we will see after we take you to Madwaleni". So that man assisted me, took me to Madwaleni. So I was admitted there. There was no doctor, but the staff nurse assist me, because they know me, they were very curious to assist me. That man drive back with my brother and my wife's brother back home. So after that I slept at Madwaleni, they gave me injection and tablet to make me sleep. So I slept, and after that, (the next) morning I was awakening, and phew. . .I was well. But something was lost in me, thinking of how did I get here. You see (the day before) I knew I wanted to go to Madwaleni, but after that injection and tablet I was lost in all that had happened, I couldn't remember the day before. Then the sister came with another tablet, I just drank it. They wanted me to be seen by the doctor, so the doctor admitted me for a week. So I was admitted at Madwaleni, the doctor said it was stress, so asking me what was happening in me. So I told the doctor that it was that divorce. It was misunderstood between both, because there was an interference by her sisters. So we took long time fighting about that, because I say "when we married we say we will apart from our parents, my parents and your parents will be left away, and we will be together as one man. But now you involve your parents in our marriage, but not willing for mine (my parents) to come in." That started to stress me. So it started hurting me up until I started to be stressed.

Shortly after he was dismissed from the hospital Khaya started experiencing strong stomach pains and severe hiccups. For this he was referred to the tertiary hospital in Mthatha, where he saw a Ghanaian doctor:

> *He could see that there was an ulcer in my umbilical cord side. So he tried to help me, and the medication I was given it was called lakomotiv[8] , it's like ibuprofen[9]. You see ibuprofen is a red tablet, a round, that is for bones, arthritis. But lakomotiv is for stress and hiccups, because I started hiccupping. Strongly hiccupping. So he gave me maxolon[10] gel, and another maxolon tablet 400. So I used them. That doctor suggested me that it should be sometimes surrounding by the devil spirit. He said, "You need to go to the traditional healers also, to try to trace this bewitched, because there should be some bewitched surrounding you."*

The tablets helped him, and he was also instructed to eat a healthy diet, which he says he does to this day. After this episode Khaya's wife persisted with the divorce. Despite the advice of family and friends to fight for his marriage, he decided to let her go:

> *I said to people; "God is there looking after me. I don't want her back to me, she dislikes me, so I don't want to force myself on her. If God save me from dying on her hands, it's good, we must grow apart. God will guide me." It is when I started to think about theology. I was already a Christian, but now I start applying for the theology in school at Roodeport. I got my first certificate of recognition, and I got my junior diploma in biblical studies. Mandela was released. I came here (back to Madwaleni) before Mandela was released.*

Although he agreed to the divorce, it weighed heavily on Khaya:

> *Really my dignity was far because of that divorce. Because all the people here they liked that lady, and you see to marry sometimes a person of the neighbours, when it's coming to divorce cases you man become an accusable person. Everyone gets involved, accusing you and pointing fingers to you because you are useless; you cannot stay with your wife. So you see your wife now has decided to divorce you because you don't care about her. So that hurt me! That is the thing I disliked in my life. But carrying on with the Christian spirit, I say I will never leave Jesus; I carry on.*

In 1999 Khaya married his second wife:

> *Now. . .Mandela was released, we went and casting our votes, and we live, and we try to build our house. When my wife was pregnant for second born she built that pink house. My wife assisted me. I was working now, starting to becoming happy. What*

[8] Comment from psychiatrist 2: “I am not sure here. Possibly haloperidol or chlorpromazine (trade name largactil). These are both antipsychotics but also used in low doses for nausea and vomiting.”
[9] Comment from psychiatrist 2: “Ibuprofen. It is an anti-inflammatory. It is used for pain and inflammation.”
[10] Comment from psychiatrist 2: “Metaclopromide. It is an antiemetic, used for vomiting.”

> *makes me happy now is that that kind of battle is over. I do have my lovely one, my wife who loves me very much, and she is caring for me, and she is getting me children. Now I know where to put my money, who is going to help me, who is looking after me if I am dirty and need to be cleaned, who is looking after me when I am tired, want to assist me by cooking me food, cleaning my clothes, everything! Who is going to be looking after my belongings. That makes me very happy, because my wife is loving me and show that kind of love. I started to change. Really, to be honest with you, my complexion, my skin, was black, black, black, black, like shoes. But after I got this wife, really I became a man, I am starting to be respected.*

Khaya and his second wife later had three children, and they are still married. They both continued their education and Khaya also started a career in theology as a preacher and a minister. They were living away from Madwaleni, in a bigger town further north, for a period of time, and during this time, while Khaya was working as a minister, his father passed away. The church he was working for did not allow him to take time off to go and attend the funeral, which affected him very much, and lead to another episode he describes as "stress":

> *That hurt me! I was so stressed! . . . I was asleep in the mission. When I was supposed to get up in the morning, I couldn't get up. I was feeling. . .my neck was just like loose. When I try to turn my neck, it's like my eyes will be torn off. I feel that my stomach was very, very empty, like it's more than five days not eating, but I had eaten last night. So I just try to turn my head. I have my phone, and when I am trying to phone, I couldn't voice any word, so I was just using SMS's. Fortunately, the hall doors was not locked. I couldn't speak. I was trying to speak, but there was no voice. So I phone someone by SMS'ing, he came around and parked the car in front, opening the doors, so by the time there was a lady coming just for cleaning the house. They saw me, and they try to assist me, carrying me, I couldn't walk. They put me in a private car and took me to the clinic, and at that clinic there was a Sotho-speaking lady who assisted me, like that doctor in Mthatha. She gave me that kind of food modification, that I take now, and she gave me a tablet called Redac[11]. My pressure (blood pressure) was too much. So she gave me that tablet to put under my tongue, and injectioned me, and I slept for almost three hours, and after that I felt good. But still couldn't speak, I couldn't move my teeth, and my mouth was not moving. She gave me a book to write in, and I write what is happening. I can write, but I can't speak. That sister didn't call doctor, she was professional sister (professional nurse). She could get me some medication, trying to*

[11] Comment from psychiatrist 2: “Hydrochlorothiazide (Ridaq). It is a diuretic used for treatment of hypertension (high blood pressure).”

> *give me something to chew, up until my jaws can move, and I could speak again. Immediately when my jaws could move, it is when I could speak again. She sprayed me with something to help my jaws to move[12]. This was after I had slept for three hours, and after that it took almost another hour for me to be right and speak again. Then I was back to normal and everything was clear to me, and I knew what happened, I could remember, think everything is ok.*

In the years to follow, Khaya and his expanding family moved from one place to another, depending on where the church sent him to work. Finally, in 2009 he was ordained as a reverend, and he started a ministry in the Madwaleni area. To this day he lives in Madwaleni. In the Madwaleni context Khaya and his family are seen as a family that prospers and does well. He is a respected member of the church and the community, and he regularly gets short-term employment. He also works as a volunteer health worker. His income is not stable, but he makes enough for the family to survive. His children are in school, they have livestock, grow vegetables and keep their houses in good shape. He now experiences conflicts with other people in the community. These conflicts, he feels, comes from people's jealousy towards people that prosper and do well. People who are jealous because Khaya is the one getting jobs that other people wish they had, or that other people feel they should have had because they are older than him or poorer than him.

I asked Khaya whom he spoke to those years back and whom he speaks to today when he experiences problems and stress:

> *I talk to anyone, but what did help me was only to go to church and pray, and cry for it, and I spoke it out. That helped me, and it was when I could realise that if a person is being hurt and trying to scream, don't stop her, don't stop him. Allow him to cry and spoke it out. Because that helped me. (Back then) I was not having anyone, except my father, but my mother hated what I had done, because they loved that wife. It was unfortunate for them. Because if the love has been broken, it's like with a glass of water; if it's broken, it's broken. Same with the eggs; you pull the egg from the nest, you want to cook the egg, all of a sudden you slip and the egg is broken, there is no egg to be cook anymore, you just forget. This is what I tell them, that this is broken, I don't want to fix it, I don't want to waste God's time by asking him to fix this, this has been broken, God will provide me, and God is preparing me the right way.*
>
> *Sometimes some other people becoming stressed due to poverty, the lack of things, so you see it is not right, it is not good to see yourself as a poor person, but my first*

[12] Comment from psychiatrist 2: "I have no idea!"

suggestion to everybody is confidence and trust to God. God does not let any person to die suffering, crying. God provide you with what you want. So I can say to begging people to assist themselves in faith; that is the only solution.

For people who are not religious, where can they find that kind of support?

Well, maybe sometimes people they can support themselves. You see, sometimes maybe sometimes these unreligious people are the better person to support each other. Really, to be honest with you, you cannot expect so much from the religious people. I am telling you. And I need to be careful. On our side, as Christians, be careful. That is why there is a message from the bible that "you can love them, but don't trust them". Because we have such kind of hearts for keeping things, and people who are not religious using alcohols, drinking shebeens; they are the friends. They can fight yesterday and tomorrow they are the friends. The past is the past.

Side note on Khaya

Khaya has grown up in this community. The community knows him, and they seem to trust him and like him. In the interviews we did together he made people feel relaxed, safe and comfortable, which in turn seem to make them speak freely and open up to us. He explained the study to them well, and lowered their expectations. His English is good, but not perfect. He used words and structured sentences in ways that make them a bit difficult to understand at times, but for the most part he made sense, and he understood me well. He quickly understood the purpose of my study, which surprised me, because most other people in the community have not quite understood, mistaking intellectual disability with mental disorder for example. Khaya is a good representative of the community; he believes in and understands concepts of witchcraft and evil spirits, callings and traditional healing. These things make sense to him, and yet he was comfortable with my many questions to try and understand, and he made every attempt to help me understand. He had compassion and empathy in bucket loads for the people that we spoke to. Several of our informants he personally followed up after we spoke to them, and one girl in particular he promised to help and support in any way she wanted him to. This allowed for me to get some feedback on how some of the informants were doing after our visit with them, and it also left me with a sense of relief knowing that they were getting at least some help and support. Khaya showed a great deal of interest in my study, and he continued to thank me for all the things he learnt through working with me.

Comments from two psychiatrists on Khaya's story

Psychiatrist 1:

If an underlying medical condition is excluded, e.g. high blood pressure, a possible psychiatric diagnosis is one of the somatoform disorders (possibly conversion disorder) where psychological distress manifests physically. Not uncommonly there is an underlying anxiety or mood disorder but we do not have enough information in this case to assess that. If no comorbidity, the disorder often gets better on its own. Psychotherapy can be offered with the focus on the patient understanding the emotional basis of his symptoms

Psychiatrist 2:

Khaya suffers from conversion disorder.

6.4 Pumla

Pumla and her family were introduced to me in 2011 by a local community health worker (CHW) who knew of the family and had visited them as a CHW previously. She told me that Pumla had suffered from a mental illness. When we arrived at their home, several family members, including Pumla, were sitting on the ground outside. Pumla sat slightly away from the others, facing away from them, staring into the open space in front of her. They agreed to talk to us, but I quickly realised that Pumla was not able to answer questions for herself, and her oldest son, Andile, therefore became the main interviewee. Pumla was present throughout the whole interview, she seemed to be listening at times, and she answered a few questions in a whispering voice and with very short answers. The questions were translated into isiXhosa by a female interpreter, and she translated all the isiXhosa answers into English for me, the interviewer. The quotes below are English translations of the original answers given in isiXhosa. My colleague from Stellenbosch University, a psychologist, also sat in on the interview, and made some comments about Pumla's symptoms, and possible diagnosis.

Pumla is a woman approximately 65 years of age. She is the oldest in her household of seven people, and the mother or grandmother of most of them. The household survives on two child support grants and one old age pension. It is not sufficient for them, but it helps. They have no livestock, but they have a garden where they grow vegetables for consumption. The family has three rondavels; one for children, one for adults and one for cooking. Since Pumla became ill, Andile had been the head of the household. He told us that he is HIV positive, and is on ARV treatment. Andile's wife had passed away a few years back, and Andile is alone with the responsibility of his children and his mother. He did not have a job when we met him, he said employment is difficult. It is also difficult for him to handle the garden and all the household chores by himself. His teenage children help out sometimes when they are not in school. His cousin sometimes visits them, and when she is there she helps out with the chores.

About Pumla's mental illness, Andile told us that:

> *She was sick of the brain about ten years ago, and she has never gotten well again. She just got crazy; shivering heavily, bleeding blood from the nose and mouth, running around aimlessly, running away, being violent and not knowing what she was doing. She was a danger to herself and others. At night she thought that she was being attacked by her small grandchild and by some men in the community who were trying to kill her, but this was not real. The child was sleeping, so she was seeing things. When she was running away she was running from those people she thought were attacking her. We were all shocked when this happened. There must always be someone accompanying her now. She can communicate, but there is nothing she can do. The bleeding stopped after one day, but the rest of the symptoms lasted for about six months, on an everyday basis, before we took her to the hospital for treatment.*

They did not know what had started it. Nothing special had happened, she had just woken up one morning bleeding from the nose and mouth. After that she started hallucinating, or "seeing things", as they put it. We asked Andile if we could ask Pumla herself about her version of what happened when she became ill. He said that we could, but he did not think that she would understand or be able to answer. She did understand the question, and replied that she does not know what had happened to her. On how she felt now, she said that she still has pain in the head, like a headache. She spoke softly, almost whispering, so it was difficult to hear and understand what she was saying.

The hospital is about 20 minutes by car from the house of the family, and several hours walk on narrow paths, up and down steep hills, across a river and on roads and paths that often flood during the rainy season. There is scarce public transport in the area, unaffordable to many, and unreliable at the best of times. Pumla and her family used public transport to get to the hospital, which cost R20 per person one way. Seeing as Pumla is unable to travel there by herself, someone has to accompany her, which doubles their cost. They also have to pay R20 every time they visit the OPD at the hospital. Medication is free. Andile also said that he has to travel to the hospital himself every month, because of his HIV. He has no problems with the service at the hospital, it is good; he only wishes they did not have to pay to go there. Of their experiences seeking health care for Pumla, Andile told us:

> *At the hospital a nurse looked at my mother's head, and said that she did not know what was wrong with her, but she gave her some medicine. We were not told what it was, or what it was for, just how many and at what time to take the tablets. They also gave her painkillers for a bad headache she had, and told her to go to a traditional healer for help and medicine, and to combine these treatments. So we sought help*

> *from a spiritual healer just a few minutes' walk from our house. The healer gave my mother a bottle of something to drink; a mix of juices and herbs. After this she got a bit better; she stopped seeing things, and she shivered less. She took the treatment from the hospital for six months, during which time she had to go to the hospital once a month for follow-up and medication. After six months a nurse told her to stop taking the treatment from the hospital. She has not been on any treatment since then, and she has not been seeing things (had hallucinations) or been running around or away since then. After her illness, my mother has become very sad, she has lost her physical power, she can communicate, but she rarely does, she suffers from headaches, and she has stopped socializing. As a result, I have decided that she might as well do nothing. She now sits in the same spot every day, sleeping or just sitting there, she does not contribute to household chores, but she dresses and washes herself.*

The family says that no one ever told them what was wrong with Pumla or what had happened to make her ill. The health providers just asked the family to explain to them what had happened. Andile said:

> *I don't know what happened. She gave birth to me, and she was never like that. I have no idea what happened*.

Pumla says she now has pain in her head, and that before the disorder she was fine. She is not seeing things anymore, and has stopped running away, but she is physically very weak, and when she sits still she has a restless leg that is always moving. They have stopped all her medication, except for the painkillers. Andile said that she was now mostly a burden to the family. He wished some doctor could help her get well, or that the family could get some help with the household chores that she used to do before she became ill. She used to do housework, cook food and go to the forest to wring wood, now she does not even have power to stir the pot, and she sleeps a lot more than she used to. They do not have to be with her all the time now, like they did in those six months when she was very sick. She just sits in the same spot all day, and only gets up to pick up her pension:

> *Now she is very sad; she just sits and she never speaks. She can speak, but she never does.*

I asked Andile how other people in the family and in the community had reacted to Pumla's illness, and he said that they had never had any problems, and no negative reactions. The only thing was that she had stopped socialising, but that was her own choice.

The psychologist from Stellenbosch, who also attended the interview, said that he suspected that Pumla had suffered from acute psychosis ten years back. He says that something must

have triggered it, but the family does not know what that could have been. The headaches and the restless leg she still experienced may be side-effects of the medications she had been given. The symptoms she had experienced subsequently, and still experiences today, seem like symptoms of depression.

Their plot of land is along a road, and I passed by on that road several times after my interview with the family. Several times driving by I saw Pumla sitting on the ground on the same spot in the garden where she sat the first time I met her. She sat there staring into the air in front of her.

Comments from two psychiatrists on Pumla's story

Psychiatrist 1:

> *The onset of psychotic symptoms this late in life (+- age 55) raises a considerable concern that there is an underlying medical condition such as a stroke which could account for many of her symptoms. Pumla may now have a secondary dementia with or without depression.*

Psychiatrist 2:

> *Pumla suffers from either psychosis due to a general medical condition, or dementia. The general medical condition could be some kind of "stroke" or what we call a cardiovascular event. The "stroke" can cause either dementia or psychosis. The story sounds more like she has dementia, I think.*

6.5 Thamsile and Aseko

I met Thamsile and Aseko in 2011. I was taken to see them by a CHW who had been visiting the family for a while because, as she said, "*They are mad and drink a lot"*. In addition to me, the CHW, a female interpreter and a psychologist from Cape Town were also present in the interview. The interview was conducted inside their home, a rondavel which was uncharacteristically messy compared to other rondavels I have visited in Madwaleni. Thamsile and Aseko are a married couple in their fifties, and they were both present during the interview. The husband, Thamsile, answered most of the questions, as his wife, Aseko, was difficult to interview. She spoke when she was spoken to, but according to the interpreter she did not answer many of the questions she was asked, but spoke of something completely different and off-topic. The couple argued over several of the questions I asked, and were more or less arguing throughout the interview. On many of the questions they disagreed about the answers, and started a loud and aggressive discussion in front of all of us. Aseko was particularly loud, shouting at Thamsile a lot. Thamsile and Aseko only spoke isiXhosa, so the interview was

carried out with the help of a female interpreter. The quotes below are answers from Thamsile and Aseko, translated into English by the interpreter. In addition to the interview, I also spoke to the CHW about the family. She told me that the family was in the health system, and that is why she visited them on a regular basis. Her job was simply to visit them and see how they were doing. She explained that both Thamsile and Aseko drank quite heavily. According to her they had been drinking for many years, but since they had become “mad” they had been drinking even more.

Thamsile is head of the household, and he said they are eight people in the household; he and his wife and their six children. Their children are two sons and four daughters. Thamsile is in a wheelchair which he got from Madwaleni. I asked him what happened for him to be in a wheelchair, and he explained:

> *What happened was that a few years back I was opening the door and something in my bones clicked and I fell down, and I can no longer stand or walk. I opened the door and broke the muscle that holds my leg. The following day I went to Madwaleni (hospital) where they massaged me. I stayed for one month, and then they referred to Mthatha. I also went to the traditional healer, because once I got mad, but I was healed.*

I asked him what he meant by “got mad”, and he explained that some years before he ended up in the wheelchair he “saw” people who were trying to kill him in his sleep. This lasted for about three months. He does not know what happened to him, it just happened one night, and he could not think of anything in particular that happened in his life that could have set it off. He went to the traditional healer who gave him medicine, and he stayed with the healer for about four months. The medication from the traditional healer took away the visions. The healer did not explain what had happened to him. He said that he is still mad, but he is better:

> *Now I do not want to be disturbed or anything. Anyone who does something wrong I get very angry. I spend my days sitting down, doing nothing. I can use the wheelchair; my wife pushes me around to where I want to go.*

I asked them how the health of the family is, and they said that the health of the family is not good. They explained that:

> *Most people don't have brains. Everyone here is sick, they don’t have proper brains. They fight.*

Thamsile further explained that especially the mother and one son *"don't have proper brains"*, not all the household members. I asked him to explain to me what he means by *"they don't have proper brains"*, and he said:

> *Today, before you came, she came here and was going to beat me up. That is just the way she is. She got sick. She was vomiting front and below, and that is when she started going crazy. It is the fourth year now.*

I asked Aseko if she thinks she is mad, and she told me that it started with fits when she was giving birth, during the birth. Every time she gave birth she got fits, but she did not have fits outside her births. She also got TB after one of her births, and the TB was treated at the hospital. She said:

> *Every time someone does something bad to me and I don't want to be disturbed I go berserk at that person.*

The husband added that when she is mad she beats him up. She said that she does not feel that she is crazy; that it is only the husband that makes her angry. When she said this she was talking in a loud, angry voice, and she and Thamsile started arguing and shouting at one another. She shouts at her husband, complaining about him, explaining why she is angry at him and why she goes berserk at him. She is very difficult to interview, as she does not listen to questions, she just screams and shouts. But she is clear that she is not crazy, she has every right to be angry and go berserk at her husband. Thamsile's story of Aseko's "madness" is somewhat different from hers. He explained that she used to be fine, and one day she was going to fetch a basin outside and she had seizures. She also started vomiting and had a running stomach. He took her to see a traditional healer, and she was there for six months. The healer gave her medicine from roots and natural remedies. After six months the healer said that he could not help her, and asked Thamsile to come and get her, *"and then"*, he said, *"the brain-thing came"*:

> *When she was there she started running away and people had to go and fetch her.*

He told me that the healer had said that Aseko's mother had cut her for protection from evil things when she was young, but the protection had now gone bad because it had been done by a now dead spirit (the mother). The healer said that this is what caused Aseko to be mad. She was never taken to Madwaleni hospital for the madness, only for the TB. For the madness she only saw the traditional healer.

Thamsile also said that their son, who was in Cape Town at the time, was mad. He started taking drugs while he was away, and when he came back he was mad. Thamsile said that both Aseko and the son are mad, but Aseko does not think she is mad. The son never got any treatment, as he did not want to. Thamsile said that he still uses drugs, Dagga, but he doesn't drink. When he can't get dagga he gets aggressive, and when he smokes he gets very loud and disruptive. He tells them that he sees things, he hallucinates. But he does not tell them

what he sees. The CHW told me that the year before the son had set fire to the parents' house, and the house had burnt down. The day after the fire he had come back with "something hard", trying to knock down what was left of the walls. She said that he sometimes gets aggressive and beats up the parents.

I asked Thamsile about his relationship with people in the community where they live, and he said that people are looking at them, and when there is violence or domestic problems the community helps them:

> *I don't know if they think bad things about us, as it is in their hearts, and I do not see their hearts.*

The psychologist who sat in on the interview said that he felt that this was a family with serious domestic problems, but not necessarily mental illness. He felt that they needed help from a social worker as a priority.

The CHW said that she feels that they are mad because they are fighting and burning the place down. Other than that they do not have any "mad behaviour". She said that they were not always like this, and that their drinking had increased since they "became mad".

During the interview Thamsile brought out his health book[13]. Looking through it I saw that it only had notes connected to his visit with the rehabilitation department in relation to him getting a wheelchair. What is written in the health book is in English, and Thamsile, the patient that the health book is referring to, does not understand what the health book says, as he cannot read, write or speak English.

Comments from two psychiatrists on Thamsile and Aseko's story

Psychiatrist 1:

> *Hard to assess when a person is drinking heavily whether the mental illness preceded or is a consequence of the alcohol. Severe alcohol abuse can present with any form of psychiatric disturbance. The best way to get clarity may be for the couple to be admitted and to assess them once they are off alcohol. Ideally their disability grants should be administered by a responsible member of the family.*

Psychiatrist 2:

[13] A book that patients keep with them, where public health providers write down tests, treatments and medication prescribed for the patient.

Thamsile and Aseko both suffer from alcohol abuse or dependence. Aseko sounds like she has what we call "psychosis due to a general medical condition". The general medical condition is perhaps something like neurocysticercosis – which could cause seizures and psychosis.

6.6 Nomabali

I was taken to see Nomabali and her family by Khaya, my interpreter, who lived across the road from them. Khaya knew the family well, and he explained that Nomabali was "mad", and would therefore be a good informant for my study. It turned out to be very challenging, if not impossible, to communicate directly with Nomabali, and so information about her and her psychosocial disability was obtained from her great-granddaughter, Vuyelwa, and her daughter-in-law, Sylvia. Vuyelwa spoke reasonably good English, and with the exception of some interpretation by Khaya, conversations with her were done in English. In conversations with Sylvia, Khaya interpreted between English and isiXhosa. I followed up on Nomabali over a period of three weeks, and also went with her to one of her appointments at Madwaleni Hospital.

Nomabali is a 77-year-old lady who seems to have a psychosocial disability. She is a mother, grandmother, great grandmother and great-great grandmother. Nomabali used to work at The Haven Hotel when she was younger. She was described by family and neighbours as "very clever" (very intelligent). She speaks good English, and in her days working at The Haven she earned a good income and was able to build a nice home with several houses and rondavels and many nice things for herself and her family. Her husband passed away more than 20 years ago, but she continued to work and support the family, and they were doing well. This was until about five years ago when two of Nomabali's three houses burnt down one night. No one knows what happened; how the fire started or who started it. They just woke up in the middle of the night, and the houses were on fire. Luckily no one was physically hurt, but nothing could be salvaged, and Nomabali lost more or less everything that she had worked so hard for. The police were informed about the burning, but they very quickly closed the investigation; it was never resolved and the family never received any compensation. Two years later Nomabali's son passed away. The son used to live with his family on the plot next to where Nomabali lives, about 50 metres away. The daughter-in-law, Sylvia, and other family members still stay on that plot. Nomabali lives with her two great-granddaughters (20 and 16 years old), two great grandsons (14 and 12 years old) and her great-great granddaughter (8 months). The oldest great-granddaughter, Vuyelwa, is the head of the household. Vuyelwa's mother is in Cape Town looking for work, her grandmother is working at a hotel a few hours away, and the father and grandfather have both passed away. This leaves 20-year-old Vuyelwa with the main

responsibility of looking after her three younger siblings, her daughter, and her great-grandmother. After the fire the household of six was left with only one functioning room of no more than 10 square metres to live in. Inside this small room they have one double bed, one single bed, a cabinet and a table with cooking and eating utensils. To care for Nomabali, Vuyelwa receives some support from Sylvia and other family members staying in her household, but Vuyelwa is the main care giver. The household survives primarily on Nomabali's old age pension, in addition to child support grants.

Vuyelwa explained that the health of the people in her household is not good, mainly because too many people live in a small space, it gets very cold there, and her three siblings have to sleep on the floor. She also explained that the mental health of her great-grandmother is bad. Two weeks before my first meeting with the family Nomabali had had fits (seizures), and had been admitted to Madwaleni Hospital:

> *Doctors don't see what's wrong. She doesn't have a pressure, and she doesn't have a sugar diabetes. But she start fitting, and it's not normal. What happened is that she was in good position before. Three years ago she was fine, five years ago was a burning of two houses that side, and since then her health start being not normal. My granny* (she refers to her great grandmother as “granny”) *was not in the burning houses, but after that we noticed that it hurt her in the heart and in the mind. . . . The fire burnt all her goods. She was just staying (remaining) with the goods that were in that house we were in (when the fire happened – the house that didn't burn down). Those goods she tries them (earned them) with a lot of work. She was working, and when she stopped working at the hotel, saying that “I have the goods now”; it burnt. That's why she just become like this. It's the sadness of losing her things. And she is scared it will happen aging*.

Vuyelwa and Sylvia both explained that after the fire, for two years, Nomabali was fine, and then she started acting differently. There were, however, small changes in Nomabali's behaviour immediately after the fire, such as her wanting to be left alone. She spent most of her time for the first two years alone in her garden, she did not want to be around other people, and she slept very little. The biggest change, however, occurred about two years after the fire, which was also around the time that Nomabali's son, Sylvia's husband, passed away. Sylvia believes that the death triggered Nomabali’s deterioration; "to become mad". There were many changes in her that made the family realise that she was "not herself"; she didn't sleep at night, she wandered around aimlessly talking and singing to herself and she was scared of people and of her own reflection in the mirror. When she saw herself in the mirror she became angry, as she thought the "person" in the mirror (her reflection) had stolen her clothes and her things.

She didn't recognise her family and friends that she used to know, becoming violent and aggressive when they tried to wash her, or when they lit the fire to cook. She also became confused, mixing strange ingredients when she was cooking and urinating in the kitchen. She needed help to do everything; cleaning herself, providing food for her, giving her tablets:

> *Every morning we start recognizing strange things. She got worse and worse. It start small, and got worse and worse. She becomes tired of people, even when she goes to pay (to pick up her grant); she doesn't want people. If there are a lot of people, she just go. She can walk around by herself, she finds her way back home. Unless like that time she faint (had the fit), she doesn't know where she is. But she was at home when that happened.* (Vuyelwa)

> *It was midnight or ten or eleven o'clock in the night when the burning of the houses started, and immediately after the burning of those huts, really she started mixing things, but slowly, not for everybody to realise.* (Sylvia)

Two years after the fire, and three years before I met the family, they decided to seek help for Nomabali's unusual behaviour. At this point it was not possible to communicate with her. She did not respond to questions and could not make herself understood. They have been to the local clinic and to the hospital several times, and usually it is either Vuyelwa or Sylvia who take her there:

> *We took her to the clinic. They look for a pressure* (blood pressure)*, and they say that her pressure is normal, her sugar diabetes is normal. They say she must go to the hospital, and they just say "you must come later, you must come later" (to the clinic), but nothing happened, and one year later she start fainting, and we took her to a special doctor at Mthatha. They saw a pressure, and after they referred us to the clinic (back to their local clinic). And they (the clinic) refer to the hospital for a further assessment, because they didn't see the pressure. But we didn't manage to take her to hospital by that time. And at the fourth of this month she start fitting. She was like shaking this side* (showing how one side of her body shakes)*. And we took her to hospital and they say that they will drain water. She has a lot of water in the body. But they also didn't see anything like diabetes or pressure like we have heard that is in the body. They just admitted her for a week, and say she must come back at the end of the month.* (Vuyelwa)

> *There was nothing identified and recognised by the clinic. There was no pressure, hypertension, no sugar diabetes, there was no headache. They couldn't see anything. She was continuous doing things wrong, but when they testing her on those things and*

> *urinate (urine test) they couldn't see anything. But the only thing they failed to notice is that she must be a bit mad, but they don't know what should be the source of it. They did see that there could be problem in her mind, but they didn't see what could be the source of it. They advise us that we should repeat go to the clinic, and maybe it would be noticed what was the source. They gave her sleeping tablets and Panado; just for headaches. She didn't have headaches, but because she was a bit mad, you know mixing talking, so maybe they were just giving her such tablets.* (Sylvia)

Nomabali has been taking the medication described by Sylvia every day for three years, but it has not made any difference in her behaviour. At the last visit to the hospital they had been given some new pills for Nomabali to take until their next visit, and Vuyelwa showed us the medication. She was taking Haloperidol[14] and Thiamin[15]. They had not been told what the medication was for, just that she needed to take the pills. The first time I met the family was only a few weeks after their last visit to the hospital, where they had been given the pills to take. At that point Vuyelwa did not feel that the pills had made any difference to her great grandmother's behaviour. On my next visit, however, about a week later, the family felt that Nomabali was less aggressive and less confused. Towards the end of my three-week period knowing the family, Nomabali was visibly better. She spoke more coherently, she was less scared and much less confused. She recognised people that she had not been able to recognise previously, such as her family and neighbours, and she even recognised me from my first visits with her a few weeks back.

I asked Vuyelwa how the great-grandmother's illness had affected her and her family:

> *It has changed us because if she was not like this, I would not be responsible for this household. She would be responsible. Even my mother, she is supposed to stop working from now, because next year I will go to school, so no one will be responsible. So my mother will come back so I can go to school. My mother becomes depressed after the granny is like this. She is worried, and call every time, that "how is mommy?" She want to come back home.*

When asked about the reactions to Nomabali's illness from other people in the community, Vuyelwa said:

> *(Some) people they come here (to visit), but others they say like 'she is a witch'. Because she is saying things that people can't understand. But family members they*

[14] Haloperidol is used in the treatment of schizophrenia and in the treatment of acute psychotic states and delirium

[15] Thiamin is a B-vitamin supplement: A lack or deficiency of thiamin can cause weakness, fatigue, psychosis, and nerve damage: http://www.nlm.nih.gov/medlineplus/ency/article/002401.htm

do understand. We don't think she is a witch. People who live close to us they know that she won't hurt anyone.

This was also confirmed by Khaya, who told me that many people believe that Nomabali is a witch, especially people who do not know her. They think so because of the way her behaviour has changed, and because she goes around talking and singing without making sense and without talking to anyone in particular.

To get to the hospital the family has to rent a car with a driver for a day, which costs R400. To get to the local clinic they take a taxi, which cost R18 per person one way. She cannot go alone, so someone has to go with her. On the follow-up visit to the hospital, at the end of the month, Khaya and I went with them. We travelled by car for approximately one hour to get to the hospital. On rainy days and during rainy periods it takes longer, as the quickest road to the hospital floods and becomes impassable. At the hospital people are given appointment dates, which means that on that date they can be seen at any time, or worse case not at all, if the doctors do not have time to see all the patients before the hospital closes at 5:30pm. They will then be seen first thing the following morning, and will have to sleep at the benches or on the floors of the hospital overnight. We arrived at the hospital at 9:30, got a stamp in Nomabali's health book to confirm their arrival, and were told to go and sit in line outside the doctors' offices. There were two community service doctors on duty. At 1pm both doctors went for lunch, only to return at 3pm. Close to 5pm Nomabali was number nine in line to see the doctor. At this point Khaya came to me and said that it was highly unlikely that the doctors would be able to see her on that day at all, given that they were going off duty at 5:30pm. He asked me to please accompany him to ask the doctor to see Nomabali before the other people before her in the queue. He believed that my presence would increase the chances of the doctor agreeing to this. Ethically I was very uneasy about this, as I was hoping to just be an observer and not a participant in Nomabali's health seeking. There were, however, a number of factors that made me decide to assist Khaya. First, the last transport from the hospital to Nomabali's home had already left for the day. This meant that they would either have to stay overnight at the hospital, or they would have to drive back with me and Khaya in my bakkie. We were eager to start the one-hour-drive back as quickly as possible, as it was getting dark (and it is not advisable to drive in the dark) and rain was threatening to make the roads back impassable. Second, I knew that for them to stay overnight at the hospital would be troublesome both for Nomabali, as well as for Vuyelwa, given Nomabali's current state of mind and her behaviour. Khaya and I went into the doctor's office, and he quickly agreed to see Nomabali and Vuyelwa before the other patients in the queue. At the very end of the day Nomabali was seen by the doctor. Both Vuyelwa and Nomabali were very uncomfortable waiting in line all day. Nomabali constantly wanted to get up and leave, and Vuyelwa had to hold her in place by force. If they

left they would lose they place in the queue. Vuyelwa struggled to keep Nomabali sitting down, and she constantly got up and started wandering around, aimlessly, talking and mumbling to herself and speaking incoherently to other people in the waiting room. People were staring at her, looking confused, surprised and even a little scared of her strange behaviour. When they could finally see the doctor, the visit took no more than ten minutes. Khaya and I were invited to come with them to see the doctor, a young isiXhosa-speaking man. The doctor communicated with Vuyelwa, asking her how Nomabali had been since her last visit to the hospital. Vuyelwa explained that she had been a bit better, and the doctor said that she should double her dose of medication (Thiamine and Haloperidol). On Nomabali's last visit to the hospital, when she was hospitalised for a week because of fits, they had taken a blood test to test for neurocysticercosis (NCC). This was written in her health book. The doctor called for the results of this test, but it was negative. He suggested that the fits may be due to her old age. They were told to come back to the hospital when they ran out of medication. When I later asked Vuyelwa for how long they had been give medication, she did not know.

About two weeks after the hospital visit I asked Khaya how Nomabali was doing, and he told me that she was better:

> *She is no longer roaming around so much; she sits still, sleeping much more. This is a sign that her medication is starting to work. She is still confused. Sometimes she will, for example, remember me, sometimes she won't. She sleeps much more than normal people. The sleeping is good, she stays in one place, can be controlled, and it's a sign that the medication is working.* (Khaya)

Vuyelwa wishes that the clinic and the hospital would pay visits to her great-grandmother, instead of making the family travel to the hospital every month. It's difficult for them to move Nomabali, and it is expensive. She also wishes that there had been a psychologist that had visited Nomabali after the fire, someone *"that could take these things away from her heart. Then she couldn't be like this."*

As part of the interview with Vuyelwa we also had a conversation about her perception of various mental health terms. I asked her if she felt that her great-grandmother is happy, and why/why not. Her response was the following:

> *No, she is not happy. . . . She is tired of everything; she is always tired of everything. She doesn't want to have anything happen to her. Like when you call her; (she) just become angry. That's why I am saying that she is not happy.*

I asked her how she would describe being happy:

> *When someone is happy, you can see when you talk to her that she doesn't become angry. She is always communicating to you. Positive things. She is just saying positive things. When you talk to her you see that this person is happy, like nothing bad.*

On what makes her happy, herself:

> *Staying in good place, like staying healthy it makes me healthy. A good place in my life, being healthy. Something that will make me happy is being successful in life; doing my studies well and going and do whatever I want. Like, further education. Like, I feel happy now because I got a bursary and can do my education.*

Previously in our conversation we had talked about her great-grandmother "having nerves", and I asked Vuyelwa how she can see that she "has nerves" and is nervous:

> *She is nervous because she will become even tired of you staying at this house. There is another. . .her sister's husband is staying at that house. She doesn't want him! If he comes to say "let me wash you", she doesn't want that. If she go to the mirror, she thinks that it will hurt her. If you say "go to urine there", she doesn't want that.*

We talked about being a worthy or a worthless person, and she was familiar with those terms. I asked her how she sees herself in terms of that, and she said:

> *No, I can't say that I am worthy. I wouldn't say that I am worthy! Because there is no income in this house. We just depend on her old age pay. We have to . . . (cannot make out what she is saying) with that money, we have to take children to school with that money. After there is no money, we are just waiting for another old age pay. . . . And we are sleeping in the same room. No one can say that "I must go to sleep in that room".*

We went on to talk about confidence, and Vuyelwa said that she has confidence in herself:

> *I have confidence that I can make the change in my family, I can make the change in my community. Through education.*

On her perception and experience of depression she said the following:

> *Yes, I understand depression like someone who feel like she might be distressed, depressed, due to loneliness, due to losing trust from someone else, thinking of someone is against you so you're depressed. I think that my siblings, they sometimes comes depressed. Because this time I think they worry that they won't have any clothes for Christmas. Like they are depressed now they are calling their mother, their father,*

> *to say"father, buy us clothes for Christmas". They are just worried by now. I think they are going to get new clothes for Christmas. . . . They get depressed worrying about money. My mother becomes depressed later on, after the granny is like this she becomes depressed. She is worried, and call every time, that "how is mommy?" She want to come back home.*

Vuyelwa is not familiar with the term "hallucination"; she does not know what it is. I explained to her that it is about people seeing, hearing or experiencing things that are not real, or that other people cannot see, and I asked her if her great-grandmother has ever hallucinated. Vuyelwas said that she never has.

Comments from two psychiatrists on Nomabali's story

Psychiatrist 1:

> *Diagnostically: There is not enough information to confidently narrow the diagnostic categories, however, Nomabali does appear to have a severe psychiatric illness which includes psychotic symptoms. The differential diagnosis is wide and includes dementia, substance induced psychotic disorder, schizophrenia, mood disorder with psychotic features, psychosis due to a medical condition, substance induced psychosis. She may even have episodes of delirium that contribute. It is interesting that she had a fit and was given thiamine. Thiamine is given as a supplement in cases of alcohol dependence and fits of unknown origin might be alcohol withdrawal seizures. Alcohol dependence can also present with dementia. I would need to make a comprehensive* (health assessment) *to advice on management.*

Psychiatrist 2:

> *Nomabali suffers from dementia with psychotic features or severe major depression with psychotic features. It is quite difficult to differentiate between depression and dementia at that age, even when one sees the patient themselves, so I cannot put my money on one of them.*

6.7 Simkite

I met Simkite in 2012. I was taken to see her by Khaya, who was acquainted with her and thought she would be a good candidate for my study, as he thought that she suffered from mental illness. Khaya had made an appointment with her to meet with us, but when we were on our way to see her he explained that she had said that she did not want us to come to her home, so she would meet us somewhere else. She met us along the road, and we sat on the concrete behind a big water tank for our interview. Simkite was not comfortable with the voice

recorder, but she allowed me to take notes throughout our conversation. She could speak some English, but sometimes she was more comfortable expressing herself in isiXhosa, and Khaya interpreted. She seemed a bit reluctant, but Khaya's presence appeared to calm her down, and she was comfortable and trusting with him. Despite her reluctance, I got the impression that she was determined to share her story, and so she opened up, although with some difficulty. She started crying early on in the interview, and cried for large parts of our conversation. When speaking of certain things, she cried so much she struggled to talk, drying her tears with a handkerchief, and struggling to find the words to answer many questions. I have outlined this in her story, below.

Simkite is a 25-year-old woman. She lives with her mother, uncle (54 years), sister (30 years), brother (23 years), cousin (36 years), daughter and five nieces/nephews (aged 2-11 years). The family has two rooms and one rondavel on their land, but no garden and no animals. Her parents separated in 2002, and her father passed away in 2006. She does not know the cause of her father's death. The family survives on one old age pension, one disability grant, child support grants and her sister's income from a job as a cashier at a grocery store in the nearest town. Simkite also used to work at a store in town, but she quit a while back, as her brother did not want her to work there. She said that her brother took her bank card and her ID book, and he still keeps it. She does not know why. She said that the money is not enough for them to get by, and hence the family lacks many things.

Her uncle is disabled, and is “always not well”; he is blind and he suffers from epilepsy. The money from his disability grant is used to look after his health, and Simkite explained that there is nothing left of the grant to support the family with food. He had been suffering from epilepsy for about five years, but had only become blind about a year ago. Simkite does not know what happened to make him blind; all of a sudden he could not see. He is on medication for the epilepsy, and only rarely suffers from fits now. Although he lives with the whole family, Simkite is his only care giver, and she is responsible for looking after him and taking him to the hospital and so on. She told me that he used to drink in shebeens before he became blind, and as a result he owed R2500. Simkite has tried to pay off his debt with her bank card, but she no longer has a card as her brother took it from her. Furthermore, one of the nieces in the household, an 11-year-old girl, is HIV positive. They found out when she was three years old, and she has been on ARVs on and off since then. Both her parents have passed away, but Simkite said that neither of them were HIV positive, and that she does not know how the niece contracted the disease. The niece is in the OVC programme, and is being looked after well by the health system.

I asked Simkite about the mental health of the family, and at that point in our conversation she struggled to talk and find the words; crying and drying her tears. In a low, whispered voice she replied:

> *It's me. I am not happy at all, particularly at home.*

She said that she has felt like this since 2006, but she has not talked to anyone about it. The source of her spiritual pain, she says, is linked to her sister's death in 2006:

> *She loved me, loved the children. It hurt much. My sister, we used to stay together at home.*

Her sister had left home many years back, moving to Durban:

> *The conflict with the family started when I was very young. I was six years when my sister moved up to Durban. I cannot say why the conflict started, as even when she was in Durban and after she passed away it was still like that.*

In 1998 the sister had come back home from Durban with a baby, but the family would not accept her and the baby. Before she died, the sister had asked Simkite to look after her child when she passed away. Simkite wanted to do this very much, but she found it impossible because the family did not accept the baby:

> *I don't know why. I was still young. She asked me to look after the baby, but the family did not accept the baby, so the baby went to live with its father. This made me feel very bad. They (her family) don't want the baby.*

She feels that her family is against her, that they don't support her. It makes her feel very bad that her sister's child is now living with its father's family, as the father has also passed away. Her relationship with her family has been bad since 2003/2004, but when I spoke to her it was particularly bad, and had been so for a while:

> *I realised there is no room for me in the family.*

At home, Simkite said, she feels unhappy, uncomfortable and alienated from the family. The conflict is primarily with her sister, brother and mother who live in the same household as her. Crying, she explained:

> *But it's my home. It's not like that daily, but very often. I am a Christian. It is not every day, but when the situation comes it's a big issue. Like when I started getting saved (as a Christian/started going to church), going to church, they don't want me to go to that church, so they force me not to go. They deny me access to go to that church. I don't*

> *know why. There is shouting, beating, and so on, it happens. They are sometimes violent against me. In 2009 I got pregnant, I have got one daughter. My brother chased me away from home when I got pregnant. I ran away to Mthatha, and stayed away for two months. Then my mother called me and asked me to come home.*

She had tried to talk to another brother who does not live in their household, and he tried to help her calm the situation at home, saying they cannot chase her away because of the mistake she made in getting pregnant. They, her and her child, belong there, and must not be chased. She feels that she is not part of the family, and that it is alienating her:

> *I feel not part of the family, but they don't say that. I am there, but not part of the family.*

The incident with her brother, forcing her to quit her job and taking away her bank card and ID book, affected her a great deal. She did not report it to the police, but she had tried to talk to her mother, who would not listen. She had also told her cousin from another household in Mthatha, as she usually supports her. A while after the incident she had a stroke, which she thinks was caused by the stress. Part of her face became paralyzed, and she went to the clinic, from where she was referred to the hospital:

> *It just happened suddenly one day. I got medication, and after about six weeks I got better. I think that the stroke happened because of the conflict with my brother about my job, my ID and my card. I did not tell this to the people at the hospital though. They asked me what happened, but I did not tell.*

At the hospital they gave her some pills to take and they put some liquid in her eye. She was not offered any rehabilitation, no social worker, psychologist and, she said, *"no injection"*.

For the past year she has been talking to the pastor in her church, and it makes her feel better. She does not go to church every week, but she goes often. The church also does home-visits:

> *Last year when I had a stroke, they came to my home to see me, but my brother would not let them.*

She said that she feels a lot of sadness, and that *"my heart started to feel pain"*. She feels better when she can talk to someone, though, and in addition to the pastor she also speaks to her cousin from Mthatha, which helps her feel better.

She also has a sister who is married and living in another part of Madwaleni. This sister once tried to come and rectify the situation at home, but the mother did not listen; *"she is not that kind of a person"*, Simkite said.

After Simkite had her baby she stayed with her cousin in Mthatha. She went to stay there after her brother chased her away from home because he did not approve of the baby. When I asked her why she decided to come back from Mthatha she said that was because she does not have family in Mthatha, and she had to go home to her family. She said that she was afraid that if she was to live somewhere else, she would be denied access to home. Also, if she goes to social development or the police for help, she is afraid that they will come to her home to assist, and after they leave she will be left alone again with the family, and she thinks it would make things much worse. Furthermore, being her uncle's main care giver, she thinks that he would suffer if she left, as she does not think the other members of the household would look after him:

> *Even him; they don't care about him. He has no mattress to sleep on, no blanket. I have to buy blankets for him while my mother is using HIS money. I don't have money to take him to the hospital and that.*

She told me that she sleeps well and *"manages to eat sometimes"*. She would like to get some medication that can help lift her spirits, as she feels very sad. Her daughter is four years old, and Simkite said that she is still too small to notice the conflict. The child's father is her ex-boyfriend. Now they have contact only because of the baby. Simkite has not told him about her situation at home:

> *I don't want to tell him of this situation. I don't want him to sympathise for me. I don't like it.*

In the interview we talked about her sharing her story with someone, and how she might feel better if she talked to someone. Khaya said that she should talk to someone, but not too many people, as it might be wrong:

> *You might lose part of yourself, sharing with too many.*

Khaya also advised her to pray, to sing, cry out loud and to use church for help. He also said that she should go to the police and tell them about her brother stealing her card and ID book, and to seek help from a social worker. He also advised her to look for a job, make her CV, to make money to enable her to move away from that home. At this point she explained that her main concern, and reason for not leaving, is her uncle. She does not want to leave him.

I advised her to seek help at the clinic, and told her about the new psychologist interns at the hospital. She said that she would go to the clinic and ask for these things, as she very much wants help to lift her spirit.

A few days after the interview, Khaya told me that he had received a text message from Simkite. He read the message to me, and in essence it was saying how glad she was that she had talked to us, and how pleased she was for our support. She also said in the message that she felt much happier after our talk.

A few weeks later I asked Khaya again if he had heard from Simkite, which he said that he had. She had called him and told him that she had gone to her local clinic after we advised her to. At the clinic she had asked to be referred to the psychologist, they had written her a referral letter for the psychologist at Madwaleni Hospital. At Madwaleni she had seen the psychologist, and she had said that it was good for her to talk to him. The psychologist had said that her family is not fair to her, and that he wants to visit her family and her in their home to help them resolve their problems. But before he does this Simkite wants to talk to her mother and tell her mother that they are coming. She had not been given any medication at the clinic or the hospital, but she felt better after her visits there.

Comments from two psychiatrists on Simikite's story

Psychiatrist 1:

> *Difficult to assess from history whether Simkite fulfils the criteria for a psychiatric disorder. Not enough info. She could have a major depressive disorder or an anxiety disorder, possibly mild to moderate since it rapidly alleviated with basic counselling. Alternatively, her response could be a "normal" one given the incredible stresses she faces. The "stroke" she describes could be a medical condition or a conversion disorder. Not enough information. In terms of further management, on-going psychological support recommended. Care giver grant should be considered.*

Psychiatrist 2:

> *Simkite suffers from major depressive disorder.*

6.8 Zoliswa

Khaya knew of this family, and he said that there was a girl in this family who was *"really mentally sick"*. He thought the family would be suitable for my study, but he was also reluctant for us to visit them, as he did not think the mother of the mentally ill girl would want to talk to us. In his experience she was an angry lady. When he told me about the family, I said that if he felt comfortable we could visit them, and at least ask if they would participate in an interview. He agreed to this, and we drove to their house. When we arrived there, Khaya asked me to wait in the car, while he went in to the house and talked to them. He was there for a long time, and I heard a very loud and at times (what sounded like an) angry woman's voice from inside

the house. Finally, Khaya came back out and said that the woman had agreed to talk to us, but not now, because her mentally ill daughter had run away the night before, and we should wait until she got back to talk to them. She had promised to call Khaya when the daughter came home, and we could arrange to meet with them. While Khaya and I were sitting in the car outside the house talking, the woman came out of the house, and looked at me curiously. She said something to Khaya in isiXhosa, and he said, *"It's ok, we can talk now, come; let's go."* So I followed the two of them into the house.

We were invited into the only rondavel on the plot of land that was in one piece. There were two other rondavels there, but one had a broken roof (grass thatched), and the other had a partly broken iron-sheet-roof, and a collapsed wall. I was told that no one was staying in the two broken rondavels. The third rondavel, that we were invited into, was a normal sized rondavel with a thatched roof. It was not in good condition, with worn paint on the outside, and caved in flooring on the inside. The furniture looked old and un-kept, with dirty blankets and clothes lying around, and uncharacteristically dirty for a typical Madwaleni home. There were three single beds in the room, and on the one bed two small children were sleeping. Towards the end of our conversation one of the children woke up. I was told the child was almost two years old, but she looked like she was less than one; very underdeveloped, with hardly any language or even attempt at language, other than crying.

We were invited to sit on one of the beds, while the woman herself sat on a small bench. At one end of the room was a table with some kitchen utensils, pots and pans. The woman did not speak English, so Khaya translated for us. The interview was recorded and the English was transcribed verbatim.

The woman, Novusile, is the mother of Zoliswa, the girl Khaya referred to as mentally ill. Novusile is head of the household consisting of ten people. She is not married to the father of her children, but they have a good relationship and he spends time with his children. He lives in another community. She explained that because two of their three rondavels were being renovated, all ten of them were currently staying in the one rondavel. The family survives on one old age pension (Novusile), one disability grant (Zoliswa) and three child support grants. Novusile also has an adult son who lives in Cape Town, but he does not contribute to the household economy as he is suffering after his spaza-shop was robbed and he was shot a year earlier. He is still in Cape Town, but he is no longer working, and his health is bad after the shooting.

The family does not have a garden or animals; they buy all their food from shops in town.

Novusile told me that about eight years ago, when she was 14 years old, Zoliswa "started becoming mentally ill":

> *She started just afraid, experiencing some three people coming towards her. It was not real. She was seeing. . .visioning. It must be eight years back. She started to run away after that. And I (the mother) was assisted by other people to chase her. She used to call those three women she saw, she used to call them with their names and cry and scream and running way, until I tell people to catch her. And then we fetch her, and we used to use the rope to let her down (calm her down). She stated that, as we ask her what these women said to her; "they say they want me to go with them, 'let us go', so they pull me." So when you see her you see that something is happening, but you don't see what is happening. But you see that she is not alone, she is fighting, because they drag her. She was afraid because they drag her, you see?!*

I asked Novusile if she knew what had happened to make Zoliswa become mentally ill. Novusile was under the impression that the illness started when the family, along with the rest of the community they lived in, were forced to move due to a migration of the community ordered by the government. The whole community they lived in was moved to another area where there was already an established community, and this caused quarrels over the land between the old community and the new community. The neighbours in the new community started to chase Novusile and her family away, saying "you use our land, we want our land, go back where you are from!" The quarrel was particularly heated with three women in the new community, and those are the three women Zoliswa saw in her visions. Novusile explained that this was the start of Zoliswa's mental illness, and what was at the core of it. She felt threatened and afraid when she thought of those three women, and when she saw them in her visions she started running away, crying and calling people for help:

> *That is the kind of sickness. Mad! Because she just run away.*

Novusile explained that the family decided to seek help from a spiritual healer belonging to their church. Talking about why she decided to go to this particular healer, Novusile said:

> *It was said to me by some other people, they suggested that I take this lady to that man, because that man used to help people with that kind of diseases or sicknesses.*

The spiritual healer gave Zoliswa water that had been prayed for, but after three weeks of this treatment she was still the same, so Novusile decided to discontinue the treatment and rather take her to the hospital:

> *The only thing that assist her to become calm is that we take her to hospital, and the hospital they give her injection, and cooling down she realised that "there was something wrong with me". And then she became right again. So, only after the injection she realised that it wasn't real (the visions). But before the injection she thought that they (the three women) were real.*

Zoliswa was admitted to Madwaleni hospital for a month with the explanation that she was stressed. At the hospital she was given pills (isiXhosa: *ipillis*), but Novusile could not say what pills they were or what exactly they were for:

> *I couldn't know exactly, because the person is not here (the daughter herself) and she knows very well what kind of medication. She is an educated somebody, Zoliswa.*

She got a bit better after the stay at the hospital, but not completely well. So her brother who stays in Cape Town called her to come to him. Novusile explained why:

> *The brother; I told him that "your sister is continuously to not becoming better, so I need your help". So that guy wanted to take his sister further to see some other spiritual healers and other doctors, if possible. That was the kind of assistance to help his mother. So he did that, and then he takes his sister to the spiritual healers in Cape Town, but there was no help. She was in St. John's faith mission. So they used to pray for the water and give her. But it didn't help.*

After the failed treatment from the faith healer the brother took Zoliswa to his local clinic in Cape Town. The clinic referred her to Karl Bremer Hospital (also in Cape Town) where she was admitted for one month. From there she was transferred to Tygerberg Hospital (tertiary hospital in Cape Town), and she became much better and stayed better for a long time after this. I asked Novusile if she knew what they had done at Tygerberg to make Zoliswa better:

> *To be honest, I don't know, but it helped.*

At Tygerberg she was given a transfer letter for her to continue the treatment at Madwaleni hospital. She was to continue on the medication given to her at Tygerberg, and the medication was to be administered by Madwaleni. Then about three years ago she fell pregnant and had to discontinue the medication while she was carrying the baby. After the baby was born about two years ago she started taking the medication again. This medication has been very helpful for her.

> *It was said that it might affect the baby inside the womb if she took it, that's why she didn't take it (during the pregnancy). She was normal herself during the pregnancy, when she was not on medication. After the pregnancy she started the treatment again.*

> *She started to become mad again maybe four or five months ago. The problem now; the medication is good, it's ok, it's working right IF she is utilising it. But the problem is she is moving away, she is not staying with us. She is running, she is fighting, taking any object, want to kill anyone in front of her, she is hitting, she is angry. It's repeated again, seeing those three women. So, one of the three women has died recently. But the other two are remaining, being seen by her. It is when it started again. I don't know what can actually be done with my baby to be healed. I was hit by her. When that started; shouting and becoming angry at everybody, and is calling that two ladies, both by names. And when you come to catch her she is taking any object, throwing it at you. She is very aggressive.*

Novusile said that recently there had been another quarrel about the land, and Zoliswa's symptoms came back when the quarrels started again. This time the quarrel was with members of her family who wanted to build a church on a piece of land belonging to her. Novusile had been fighting for the land, as she wanted one of her sons to use it when he got married. The quarrel involved the village headman and the police in the past, and had more recently gone to the courts, where it was resolved that Novusile was the rightful owner of the land. The quarrel is mainly concerning Novusile, but Zoliswa is very affected by it, and shortly after the court case had finished she started becoming mentally ill again:

> *No any daughter or son of mine is involved in this quarrel. I stand alone in this. They are not involved. But the symptoms came back when the quarrel started again. What I realise is that the problem of Zoliswa is starting exactly after the quarrel of the land, so her minds and thoughts are taking in that seriousness. So with Zoliswa it is coming into her head, and after a while she reacts. That is why she became stressed sometimes. It's the stress that makes her like that.*

This happened only a few weeks before I met Novusile. At the time Zoliswa was still on her medication prescribed at Tygerberg, but because her symptoms had escalated, she often forgot or refused to take her medication. Furthermore, Zoliswa had recently become pregnant again, and as a result the doctors at Madwaleni hospital had changed her medication. Novusile insists, however, that Zoliswa became pregnant while she was using the old treatment, and the pregnancy happened after she became mentally sick again.

After the symptoms got worse Novusile also took Zoliswa to a traditional healer:

> *I took her to the traditional healer, using traditional medicine, like herbs. Why I took her to that person; I just tried to get some faster assistance because, of course she is using this medication from Tygerberg, but I see this kind of sickness is continuous.*

> *Sometimes it's becoming cooler a bit, but all of a sudden it is coming up. So I decided to take her maybe sometimes to that traditional healer. But there was nothing happened there, there was no assistance. He did give her some medication, but it didn't help. For two weeks he tried to help, but it didn't help, it became worse. Now it's getting worse and worse. Last night, before she departure away, she was taking everything, hitting me (the mother – she is showing us a bruise). I don't know where is she now.*

The evening before I met with Novusile, Zoliswa's behaviour had taken a turn for the worse. Novusile told me what happened:

> *She started to feed the children, while they were saying they don't want to eat. So she started to hit them and force them to eat. So she started to chase me, claiming that she must stay here, but I must go out. "Otherwise I will kill you" (the daughter said). And she is taking some knife, running after me.* She said s*he wanted to use this knife to kill me, and her brother. She is mad. So after that quarrel between us I just took two sticks, trying to hit her, but I didn't hit her, she ran away. She just took a blanket and ran away. She hear the car sound passing by; I assume maybe she got on that car. I don't know where is she now; I haven't seen her since.*

I asked Novusile how Zoliswa's illness has affected the family, and she explained to me that many times she has come with her daughter to the hospital, the traditional healer and to Cape Town; staying with her, nursing her and looking after her. But more than that, Zoliswa's illness has affected Novusile's mental and physical health:

> *I realised that there was a change in my life – feeling painful in my heart, and as a result I do have some hypertension. As now I have been admitted in hospital and get some medication; high blood pressure medication. I am still using now.*

Talking about her own mental state, Novusile said that because of the situation with Zoliswa she feels very unhappy:

> *I am very much unhappy, and I am becoming slender and thinner; I am slimming now because of the kind of situation. Really it's not well in me because of this; mainly because of the daughter, and the situation of the land. Because every time this situation of the land came it's affecting my daughter. So that's why I am not happy. When Zoliswa was quite right I was so beautiful and fat, and people were imagining of my body so fresh! But started when Zoliswa started sick, my heart started down. I was so let down by experiencing such thing again, and that is why I started slim. I don't have enough time to eat. Even if I want to eat, by the time I have the time I don't have chance to eat the right food. Because I am always eating readymade food as I am out from my home*

> *working this Zoliswa problem. So this is why I started slimming, because I don't eat my own choice of food.*

I asked Novusile to tell me about these feelings of unhappiness; what those feelings are, the feelings of unhappiness that she told me she was feeling. Her explanation was the following:

> *The problem that makes me very unhappy is that this person is sick and is not staying down. And while she started this kind of sickness, she is rude, she is hitting, is taking everything, want to kill everybody. So that hurt me. Not for me to be against her, but to be painful, feeling bad about my child. Say, for instance, I don't know where is she now. And my worry is that when she goes out, she doesn't tell me where does she go. And I am very sorry thinking that one day I will be called of the body who is lying, maybe being raped and killed or has been hurt by a car. That is what worries me.*

Novusile feels that the solution to Zoliswa's problems would be for the quarrels over the land to end:

> *I think the source of this is the land, all these conflicts. It could be, because this started only after they came here and talking about this. So if they could stay away from my land, I believe that Zoliswa can be right. It is not the first time. Before it was, now it is the same. Of course, they don't talk to her, they talk to me, but this kind of talk is affecting her spiritually.*

Towards the end of the interview Khaya and Novusile described Zoliswa to me, saying that she is sweet and respected. They are surprised, though, that she is clever and remembers things, because she is so mentally ill. Khaya said:

> *What is confusing in my mind is that while Zoliswa is getting sick in the mind, mentally, she could tell you what you did to her. Which seems to me there should be something in her mind, because she is recalling – her mind is recalling.*

A few weeks after our interview with Novusile, Khaya told me that he had been in contact with her again, and she had told him that Zoliswa had come back home a few days after the interview. She had gone to stay with her brother, who also stays in Madwaleni, while she was away. Khaya had also seen Zoliswa herself at a funeral, and he told me that she was not well; she was confused, singing the wrong songs, roaming around. When it came time to eat, he had seen her eat a plate of food, and then after that she had come and complained that no one had given her any food. So she was given another plate of food, which she also ate, only to complain again that she had not been given any food. Khaya told me that he thought that she must be confused and unable to remember.

Comments from two psychiatrists on Zoliswa's story

Psychiatrist 1:

> *It sounds like Zoliswa has a psychotic illness. Patients generally are referred to Tygerberg hospital if they also have a medical illness or are treatment resistant, so it sounds like her case is not straightforward. Care would need to be the right medication and ideally social worker assessment of the home situation including care of the children.*

Psychiatrist 2:

> *The young lady, Zoliswa, sounds like she suffers from Bipolar Disorder. And her mom suffers from major depression. Really very sad story, yet so common, of poor outcome due to non-continuous treatment.*

6.9 Concluding statement

In Chapters Five and Six I have presented a description of care for people with psychosocial disabilities in Madwaleni. While the contextual study provides a broad overview of Madwaleni, the context, culture and the potential care strategies available, the case studies provide thick, in-depth descriptions of individual experiences of care. In the next and final chapter of this dissertation, I provide an analysis across the six cases and a discussion of the findings against the conceptual and empirical framework presented in Chapters Two and Three.

Chapter Seven: Cross-case analysis and discussion

7.1 Chapter outline

The overall objective for this study was to explore structures of care for people with psychosocial disabilities in Madwaleni. In this chapter, I will describe and discuss the various care strategies available in the context of the study site, why the various strategies are chosen and with what outcome. It is crucial to explore the cultural and contextual factors that influence care giving and seeking. The basis for choosing strategies for care is the understanding of the person and the condition in need of care, and I will therefore start Chapter Seven with an introduction to various conceptualisations of psychosocial disability derived from the theoretical background and from the data material. I will then go on to explore care structures and strategies, as well as the barriers and facilitators to these. Finally, I will address the strengths and potential limitations of the study, and how they have been dealt with to reduce their impact on the final outcome and to ensure the validity and trustworthiness of the data and the project as a whole.

This dissertation explores the individual, cultural and contextual factors that determine care seeking, care giving and care receiving for people with psychosocial disabilities in Madwaleni. These factors are intertwined and form the basis for understanding and dealing with psychosocial disability appropriately (Keikelame & Swartz, 2013b). It is outside the scope of this dissertation to study the relevance, quality and effectiveness of the different care options.

7.2 Conceptualising psychosocial disability in Madwaleni

It is widely acknowledged that the way mental disorder and disability are conceptualised impacts on the way people are treated (Braathen et al., 2015; Bricher, 2000; Harpur, 2012; Kittay et al., 2005; Siminski, 2003). Therefore, in order to understand structures of care for people with psychosocial disabilities, I will first explore conceptualisations of psychosocial disability in Madwaleni. I will also discuss how these conceptualisations impact on care seeking and care giving.

Two overall theoretical approaches to psychosocial disability have been found particularly relevant to this study, namely approaches to disability and approaches to mental disorder. Both mental disorder and disability are debated concepts, with no unified definitions for either. The concept of psychosocial disability for people in Madwaleni is complex. Three major approaches are found in the data: a disability approach, a psychiatric approach and a cultural approach. These approaches will be discussed in the sections below.

7.2.1 Disability approach

It is widely acknowledged that mental disorder can cause disability, and that disability can cause mental disorder (Andrews & Titov, 2007; Gureje & Stein, 2014; Patel & Stein, 2015; Prince et al., 2007). Severe mental disorders *are* disabling in nature, as the data presented in this dissertation also illustrate. It is however difficult to determine when something is within the range of "normal" mental health, and when something constitutes a disorder. Gureje and Stein (2014) argue that something becomes a disorder when it presents as a challenge or barrier to people (Gureje & Stein, 2014), at which point one may argue that it presents as an activity limitation, and thus fits within the disability paradigm. Thornicroft (2006) has argued that a disability approach to mental disorders is the most appropriate to reduce stigma and discrimination, and increase inclusion and quality of life for people with mental disorders.

While none of the informants in this study described mental disorder as a disability, descriptions of inability and dependency frequently came up. Thus, while most of the informants thought of mental disorder as separate from disability in the strictest sense, they described mental disorder as something that fits with the bio-psycho-social approach to disability. For instance, many of the health providers of scientific medicine in Madwaleni described both disability and mental disorder as "inability". The two were described as different conditions, but both primarily conceptualised from a biomedical perspective, as something wrong within the individual. It is only when we explore the cases in more detail that we see the relevance of a bio-psycho-social disability approach to psychosocial disability in Madwaleni. Through careful examination of the case studies, it becomes clear that the suffering of the people discussed in the case studies stem from more than psychiatric conditions. The suffering and disablement is grounded in cultural and contextual processes resulting in activity limitations and participation restrictions. It is not so much their inabilities that disable them, but a complex web of influences ranging from stigma, self-esteem, poverty, gender roles and so on. "Inability", to use the term used by informants, is only part of the story.

It is evident from the data that many of the informants suffering from mental disorders experience activity limitations and participation restrictions. Pumla, for example, stopped participating in the daily activities of the household and in social activities when she became ill. She was, however, able to wash and dress herself, and thus she had abilities. Without nurturing her abilities, and by placing emphasis on her inabilities, her family and the health system contributed to restricting her participation. From the hospital, she had received medication to reduce her symptoms, but once the active symptoms were gone, there was no follow-up. Aside from medication, Pumla had not received any other assistance from public health services, although there is good evidence to suggest that she would have benefited

from services such as occupational therapy and counselling (Reed et al., 2010; Watson & Swartz, 2004). Counselling services were not available in Madwaleni at the time, but she could have been referred to Mthatha for specialist psychological or psychiatric services. There was an occupational therapy department at the hospital in Madwaleni. Pumla could most likely have benefited from occupational therapy, to assist her and her family in coping with her illness, in order to increase Pumla's ability to participate and her family's ability to include her. However, it seems that the health providers, including the two psychiatrist that were consulted on the case studies, do not associate mental disorder with disability, and thus it is possible that they do not see the relevance of such services for patients with mental disorders. There is, however, ample evidence to suggest that there is a positive correlation between occupational participation and mental well-being (Pereira & Whiteford, 2013; Reed et al., 2010; Vessby & Kjellberg, 2010; Watson, 2004a, 2004b). In line with this, one reverend believed that there is a strong link between mental health problems and unemployment in Madwaleni. Unemployment causes poverty, it makes people feel like they are not useful, and this may be associated with family problems, alcohol and drug use and consequent mental health problems.

7.2.2 Psychiatric approach

Public health services in South Africa primarily takes on a psychiatric approach to mental health. From this perspective, mental disorders are identified through common symptoms, described in manuals, such as the DSM (APA, 2011, 2013), which is used in public health facilities throughout South Africa. Several scholars have argued that DSM and other classification systems (ICD) fail to fully account for cultural constructions for many mental health conditions, and conflict with many traditional therapeutic practices prevalent throughout Africa (Akyeampong, 2015; Akyeampong et al., 2015; Patel, 2014).

From the perspective of a universal approach, mental disorders are seen as universal biological and psychological processes that can be found transculturally (Cohen et al., 2014). From a relativist approach, on the other hand, mental disorders are seen as shaped by culture, not universal in nature, and thus have few comparative measures across different contexts and cultures (Cohen et al., 2014). Finally, from the perspective of a critical approach, there are multiple, diverse psychologies. This approach is a combination of the universal and the relativist approach, and it is thus not denying universals, but believes that there are differences in expressions of and responses to mental disorders across different cultures (Cohen et al., 2014; Swartz & Rohleder, 2008).

An argument supporting the universal approach and rejecting the relativist approach found in the data presented in this dissertation is that while none of the case study informants had been given, or were aware that they had, a specific psychiatric diagnosis, they had symptoms of

mental disorder that are arguably universal in nature. The two psychiatrists who commented on the case studies picked up symptoms of mental disorders in all the cases. The symptoms are consistent with diagnosis specific criteria for mental disorders described in DSM IV (APA, 2011). In most of the case studies, the two psychiatrists provided the same or similar suggestions for diagnoses, although it was not possible for them to give definite diagnoses without doing comprehensive assessments themselves. This supports the argument that there are universal traits to psychiatric diagnoses. However, the data also show clear cultural and contextual experiences and expressions for mental disorders, supporting the critical approach. From the perspective of a critical approach to mental disorder, mental disorders are perceived as having some universal traits, while still being highly culturally and contextually specific (Cohen et al., 2014; Swartz & Rohleder, 2008). The cultural and contextual experiences and expressions will be described in more detail in Chapter 7.2.3 below.

Common mental disorders have been said to present with many of the same symptoms in most cultures, mostly somatic at first (tiredness, sleep disturbance, aches, pains), but also psychological symptoms (loss of interest and concentration, suicidal thoughts, anxiety) are commonly reported on inquiry (Patel & Stein, 2015; Tomlinson et al., 2007). From the data presented in this dissertation it seems that subtle somatic and psychological symptoms of common mental disorders described above are generally not picked up, or not perceived as symptoms of something that requires special care. Only when a person presents with severe symptoms of mental disorder, often through behaviour that is difficult to control and manage, the perceived need for help arises. In the case of Nomabali, for instance, her family believed that her mental illness was the result of her long-lasting sadness of losing her home, her possessions and her son. Over a period of several years they had noticed small changes in her; lack of sleep, anti-social behaviour, sadness and so on. It was only when her behaviour got out of control, however, that they sought help for her. At this point she was hallucinating, running away, did not recognise people she knew, was aggressive and confused. This was when the family decided she needed help. This is in line with what has been found in previous studies from South Africa (Cheetham & Cheetham, 1976). Had she received help earlier, in the initial phases when she first lost her home in the fire and then her son, the severity of the subsequent mental disorder could perhaps have been reduced. Similarly, in Simkite's case, family conflicts lasting for years led her to become severely depressed, with feelings of hopelessness. The family could probably have benefited from help from counsellors or social services, but no one in the family asked for help, and no one offered them help. While the informants believe that there is an association between ongoing stress or conflict and mental disorder, awareness of the need or possibility to seek help appear to be lacking. The result for

both Nomabali and Simkite was development over time of severe mental disorder, which could perhaps have been prevented with earlier intervention and prevention.

In several of the case studies somatic illnesses were described as caused by mental problems such as stress and sadness. Both Khaya and Simkite experienced severe physical illnesses that they believed were caused by long-term stress and conflicts. This was corroborated by the psychiatrists who commented on the case studies, saying that the experienced somatic symptoms could be conversion disorder. However, while physical symptoms are conceptualised as linked to mental issues, they may not necessarily be seen as linked to psychiatric diagnoses. Khaya, for instance, strongly believed that the somatic symptoms, caused by stress, were initially caused by witchcraft. This will be explored in more detail in Chapter 7.2.3 below.

When patients seek help from scientific medicine for symptoms associated with mental disorder, it seems that they are looking for and expecting biomedical explanations. In several of the case studies they explained that when they sought help from clinics or the hospital for symptoms of mental disorder, their understanding was that the health provider had tested for high blood pressure and diabetes. Painkillers, such as Panado, commonly used for headaches, were believed by several informants to be appropriate to treat any problem of the head, including mental disorder. And indeed, it seems that many public health providers do prescribe such pain killers to patients who have psychiatric symptoms that are difficult to diagnose and/or manage.

The health workers in public health facilities in Madwaleni are trained in scientific medicine, which takes on a psychiatric approach to mental disorder. The picture becomes more complex, however, with the health workers who are from the same community. On the one hand, they are members of the community, sharing the culture of the community. On the other hand, they are trained in scientific medicine. An example of this complexity can be found in the case of Pumla. When she became acutely ill, the family took her to the hospital. Their perception was that the nurse at the hospital did not know what was wrong with her, but she gave her some pills, and she told them to take Pumla to the traditional healer. The traditional healers take on a completely different approach to mental disorder compared to scientific medicine, which will be elaborated on in Chapter 7.2.3 below.

Thamsile and Aseko are described, and describe themselves, as "mad". In their description of their family, they come across as a family with major social problems of poverty, aggression, violence, alcohol and drug abuse. The attention of the family and the care system is on curing the "madness" and not on solving the social issues, which, argued by a psychologist present in the interview and the two psychiatrists who commented on the case study, are probably the

underlying causes of the "madness". Informants from various churches, however, associate mental disorders with social issues such as abuse and neglect, and have formed various systems of support within the church to assist people with these issues, or to prevent such issues.

7.2.3 Cultural approach

While there are biomedical explanations for mental disorders, the experiences and expressions of these disorders are also deeply rooted in demographic, cultural and contextual factors (Kirmayer & Swartz, 2014; Lund et al., 2011; Lund et al., 2014; Patel & Stein, 2015). Thus, a bottom-up approach has been called for to provide culturally relevant descriptions of mental disorders (Patel & Stein, 2015). However, it has been emphasised that one must be careful to assume that there is one Black African or amaXhosa experience of mental disorder, as experiences are highly individual, culture and context specific (Kleinman, 1980; Lund & Swartz, 1998; Sorsdahl et al., 2010).

Conceptualizations of psychosocial disability are closely linked to notions of normality (Davis, 1997; Goffman, 1963). The further from the norm a person's behaviour is, the more he or she is considered "mentally ill", "mad", "sick of the brain", "confused", and so on. Notions of normality are closely linked to stigma and discrimination, all of which are highly cultural and contextual phenomena (Kleinman & Hall-Clifford, 2009; Thornicroft, 2006). Many symptoms of psychosocial disability, particularly the more severe symptoms, are considered outside the "normal" in most societies. Some symptoms are considered undesirable, other symptoms may be seen as less "abnormal" or even desirable. The judgement that people attach to various characteristics of psychosocial disability, however, are culturally and contextually dependent, and may even vary within cultures. Examples of this are the cognitive experiences of *Ukuthwasa* and *Amafufunyana*, found throughout South Africa, including Madwaleni (Niehaus et al., 2004; Sorsdahl et al., 2010). Both phenomena have symptoms similar to schizophrenia or depression, described in DSM IV (APA, 2011). The symptoms are considered outside of the "normal", but while *Ukuthwasa* is a condition with positive connotations, *Amafufunyana* is charged with negative stigma. The symptoms of *Ukuthwasa* are said to be caused by ancestors calling someone to become a traditional healer. If a person is subject to *Ukuthwasa* he or she has to give in to the calling and start the process of becoming a healer to "cure" the symptoms. As such, *Ukuthwasa* has positive connotations, compared to *Amafufunyana*, which is associated with illness, disorder and impairment. *Amafufunyana* is described as symptoms (hysteria, nerves, weeping, violent behaviour, suicidal attempts, hallucinations, etc.), and sometimes as explanatory models to explain symptoms (spirit possession/witchcraft). People who experience *Amafufunyana* are sometimes diagnosed with schizophrenia, and sometimes

with depression, but they rarely associate with these diagnoses, and thus often seek care from various traditional healers. It has been found, however, that people who experience *Amafufunyana* benefit from psychiatric medication, and thus some of these patients apply medical pluralism. Scientific medicine is often seen as successful in reducing or removing the symptoms, but not in providing explanations for the symptoms. Traditional medicine provides explanations that resonate more with the belief system of these particular patients. It has been argued that these explanations can help remove the blame from the patient to an outside source (witch, spirit), and thus removing the stigma (Lund & Swartz, 1998; Mzimkulu & Simbayi, 2006). On the other hand, there is contrasting evidence to this from South African studies suggesting that mental disorders are associated with greater stigma (Botha, et al., 2006; Mavundla, et al., 2009). The evidence presented in this dissertation is not conclusive to this end. On the one hand, there is evidence that the case study informants and their family members are subject to stigma related to witchcraft. On the other hand, the stigma is often attributed to an unknown outside source, with both the cause and the source of the witchcraft unknown.

It is commonly believed in many African cultures, including among many of the informants in this study, that mental disorders are caused by spiritual forces such as witches, wizards, evils spirits and ancestral punishment (Okello & Musisi, 2015). Various traditional healers provide care that have this as their starting point for the provision of care. This is very different from scientific medicine, which has a biomedical understanding of mental disorders at the core (Okello & Musisi, 2015). However, witchcraft alone is not a cause, as witchcraft also has its causes. Among the informants, several causes for bewitchment were cited, such as lack of protection from bewitchment and jealousy. Jealousy was the most commonly cited cause, and was said to be highly prevalent in the community. The jealous person bewitches the person of which he or she is jealous. As such, anyone can be bewitched, and the bewitchment can cause mental disorder. Bewitchment is also described in the literature and in the data from this project as something that happens to people who, for some reason, are not protected by ancestors (Bührmann, 1982; Sorsdahl et al., 2010). Aseko, for instance, had been protected from evil as a child by her mother. When her mother passed away, Aseko was said to no longer be protected. As a result, Aseko had been bewitched and became "mad". The blame of the mental disorder is thus removed from the person with the disorder to the person who bewitched him or her. The witch was said to be a person in the community, but it is not visible to people who is a witch and who is not. Some of the healers explained that only some traditional healers who are born with a special skill see who has been bewitched, and can cure people who have been bewitched. Based on this material, the person who bewitches is rarely identified, and as such,

no one has to suffer the blame. The underlying cause of the supposed bewitchment that caused the mental disorder remains unknown, subject to speculation and guessing.

As described above, many people in Madwaleni associate symptoms of mental disorder with bewitchment, or sometimes with the person being a witch. Behaviour such as speaking incoherently, wandering around aimlessly, seeing things (hallucinating), aggression and violence are often associated with bewitchment. It appears, however, that these beliefs are more common among people who do not know the person, while family and friends less commonly hold such beliefs. Similar patterns have been observed in other parts of the world (Braathen & Ingstad, 2006; Wan, 2003). This indicates that stigma decreases with familiarity and awareness, emphasising the local, social and relational aspects of stigma (Kleinman & Hall-Clifford, 2009). It also strengthens the theory that the best way to combat stigma is through social interaction with individuals who are stigmatised (Thornicroft, 2006), and thus it has been argued that the best way to care for people who are outside the normal is through mainstream programmes, as opposed to specialised and segregated services (Shakespeare, 2014). A foreign medical doctor had observed, somewhat to his surprise, that people in this area were generally very accepting of people with various forms of disabilities. He felt that in his Western culture people with disabilities were judged more: *"And I don't know whether that's a resignation or an acceptance so much, but I'd like to think it's more the latter".*

Studies from Africa have found that depressive or anxiety symptoms are commonly described as "thinking too much", and not as sadness, which is common in Western cultures (Okello & Musisi, 2015; Sorsdahl et al., 2010). Non-psychotic depression is sometimes understood as an illness attributed to worrying, and not something that requires help from scientific medicine, but rather help and support from family, friends, religious groups and others. Psychotic-depression, on the other hand, is often described as the result of a bad relationship between the living and the dead, best attended to by a traditional healer (Okello & Musisi, 2015; Sorsdahl et al., 2010). In many LMICs mild and moderate mental disorders are generally not perceived as requiring treatment (Andrade et al., 2013). Similar patterns were found among people in Madwaleni, where many linked psychological concepts to practical and economic well-being. For instance, depression was described as worrying about money, or concerns about how to care for a sick family member. A church leader described two types of mental illness; one caused by stress, and one caused by evil spirits. For many of the informants, various mental states, such as happiness, unhappiness, depression, anxiety and feeling worthy are described as linked to practical circumstances in their lives. Depression or anxiety are linked to worries about poverty or illness. Happiness is linked to good health, success, education, employment and income.

There is no direct translation between English and isiXhosa for many mental disorders, or for the various symptoms of mental disorders. This is clear from the translations by Khaya and the two Stellenbosch Academics, translating various English mental health terms into isiXhosa. Thus, it is difficult to accurately interpret what mental disorders people may suffer from based on their own descriptions of their symptoms or diagnosis.

7.3 Care for people with psychosocial disabilities in Madwaleni

Care is often thought of as something people need when they are ill and unable to look after themselves. This is, however, only one aspect of care as it is conceptualised in this dissertation. Arguably, all human beings need care for basic survival (Engster, 2005; Kittay, 1999). Care is essential for the promotion of good mental health, for the prevention of mental disorder, and in the treatment and cure of mental disorders. Furthermore, care is broader than health care, and includes a wide range of activities we do to maintain our world. This broad approach to care becomes relevant when we carefully examine each of the six case studies. In the case studies, we see that some are dependent on care that they cannot provide for themselves, which is described as dependency care. Others receive various forms of care without being dependent on this care for survival, or even being unable to provide this care for themselves (Kittay et al., 2005). It has been argued that only dependency care should be considered care, and that if the person is able to do the activity for him/herself, it should be considered a personal service. On the other hand, it is argued that personal services can also be understood as care, but without an obligation to care (Engster, 2005). The obligation to care is culturally and contextually defined, but with some universal traits. All human beings are interdependent, living in a web of dependency, where we are dependent on care and providers of care interchangeably. In this context, our interdependency may be a motivation to care itself. Adding to this, humans often have a special obligation to care for certain people in their network, but who these people are is to a large extent culturally constructed (Engster, 2005). In the context of Madwaleni and other similar African communities, where the Ubuntu philosophy is a large part of the culture (Engelbrecht & Kasiram, 2012; Kaseje & Mpenda, 2002; Kirmayer & Swartz, 2014), the obligation to care may extend far beyond immediate family members. Immediate and extended households contribute to care activities (Braathen et al., 2016). In Nomabali's case, for instance, she is cared for primarily by her great granddaughter from the same household. In addition, they receive support from Sylvia from their extended household in the same community. They also receive economic care from Nomabali's daughter and granddaughter who have travelled outside the community for employment, in order to earn an income for the household. In addition to the immediate and extended households, people are often part of

several communities and societies that provide care, such as clans, villages, women's groups, religious groups and professional associations (WHO, 2002).

From the broad perspective of care outlined in the literature review chapter, the data presented in this dissertation outline a number of care strategies and care providers offered to and utilised by people with psychosocial disabilities in Madwaleni. These will be discussed below, along with an exploration and discussion of how the various care strategies and providers interact and collaborate in a pluralistic system of care.

7.3.1 Care strategies

Care is culturally and contextually dependent; what is considered good and appropriate care in one context, may not be so in another context or culture (Engster, 2005; Kittay et al., 2005; Tronto, 2001). There are, however, some universal aspects. At the core, care is about meeting care needs, but how the needs are met differ across cultures and contexts (Engster, 2005), and even within the same context and the same culture, as this study has shown.

Care has been described as labour, as hands-on activity (Engster, 2005; Kittay et al., 2005; Sander-Staudt, 2011), but from the perspective of care taken on in this dissertation, not all care is labour and not all care is hands-on. Care is an essential part of most relationships; it is as much about caring for someone else as it is about allowing someone else to care for you. Tronto's (1993) approach to care has been criticised for being too broad (Engster, 2005). Engster (2005) narrows the approach, specifying that it is the aim of an activity, and not the activity itself, that defines it as care or not. Activities done for making money, he argues, are not care activities, but if they are done voluntarily in order to help someone, they are care activities. Many care givers, however, do carry out care activities in order to make money, and thus it is difficult to make a strict distinction as to what constitutes care. Of relevance to this dissertation are care strategies applied to improve mental health, and to prevent, treat and cure mental disorder in Madwaleni. The strategies applied are scientific health care, traditional healing, financial care, emotional care, occupational support, church support and care for the carers. These will be described below.

Scientific health care

In all the case studies participants had at some point sought help from the public, scientific health care system for the psychosocial disability. It is widely argued that the most effective mental health interventions require access to diagnosis, medication and skilled health workers. From the perspective of public health care in South Africa, and in the context of psychosocial disability or mental disorder, skilled health workers would be psychologists, psychiatrists, mental health nurses and social workers (Patel, Araya et al., 2007; Patel, Boyce et al., 2011).

These are largely unavailable in Madwaleni. The result is that it is at best general nurses or doctors, with only very basic knowledge of mental health issues, who diagnose and treat patients with mental disorders. Task shifting and task sharing has been argued for in the field of mental health, and has been shown to work, given availability of adequate training, supervision and compensation (Maselko et al., 2015), all of which are lacking in Madwaleni. Health workers are already overburdened, in a health system with very limited resources of all kinds. Thus, very few patients with mental disorders are diagnosed or treated in the public health care system in Madwaleni. It is likely that this is due to lack of diagnostic capacity, and not that they are less common in this particular community.

While scientific health care offers a wide range of care options for people with psychosocial disabilities, these options are not available in many parts of South Africa (Swartz & MacGregor, 2002), including Madwaleni. At the clinics, the health centre and the hospital only the most basic mental health care is available, and specialist referral is located far away with very limited transport options to get there. The psychiatric clinic that used to be at the hospital more than 20 years ago was highlighted by health workers as crucial. The political argument for closing the clinic was that mental health services were going to be decentralised; based at the primary health care clinics, rather than at the secondary hospital. The experience of both patients and providers, however, is that there are no longer mental health care services in Madwaleni. People describe a situation where acute symptoms of severe mental disorder are treated with basic drugs and injections, but with very little long-term care or follow-up. Mild to moderate mental disorders are rarely picked up. The focus is on illness and disorder and not on maintaining good mental health through mental health prevention and promotion. One medical doctor said that staff shortage meant that there was not enough time or resources to be proactive, and they had to rather be reactive and solve the problems as they were coming to them. The result is that they treat the acute symptoms of mental disorder, but do not get to the root of them. An example of this can be found in the case of Pumla, where her immediate and acute symptoms were treated, while she continued to suffer from the aftermath of her mental disorder, but with no on-going care from the public health care system.

The overall priority for mental health in the public health care system in Madwaleni is low, emphasised by one of the nurses at the hospital:

> *No one bothers about the confused people.*

The question is whether it is about a lack of concern for these issues, or if it is primarily related to systematic constraints, embedded in lack of qualified personnel, too high patient-provider ratio, and lack of equipment and medication. I would argue that these issues are interlinked. The challenges and complexities of integrating mental health into primary health care have

been highlighted in a recent South African study by Petersen and colleagues (Petersen, et al., 2016). Successful integration requires support at organisational, facility and community levels, but may end up placing added burdens on an already overloaded public health system. However, if integration is done properly, with cultural, contextual and systematic realities at the core, the advantages can be substantial (Petersen, et al., 2016).

A problem with scientific medicine and psychiatry as it is often practised is that it can be seen as being what Tronto (1993) refers to as paternalistic. This is referring to the care giver assuming to know better than the care receiver what his or her care needs are (Tronto, 1993). Indeed, the field of global mental health and psychiatry have been accused of being paternalistic, imposing views of mental health constructed primarily in the West on people in other parts of the world (Mills, 2014). This could mean that for instance people are seen to have low mental health literacy, but may in fact have a completely different conceptualisation of mental disorder, as described in Chapter 7.2 above. However, scientific medicine provides a form of care of which the care givers generally know more than the care receivers do. Nevertheless, care is not just about meeting a need and achieving a certain aim, it is about doing so in an appropriate manner (Engster, 2005). Thus, as argued by many proponents of global mental health, listening to contextual, cultural and even individual perspectives is essential to provide the best possible care, and for the care receiver to receive the care as best as possible.

Scientific medicine offered through the public health care system is a relatively new concept in the context of Madwaleni, and it is therefore not as embedded in local culture and traditions. It is clear from several of the case studies that patients often do not understand what is wrong with them and why they receive the care that they do from public health care. For instance, in the case of Zoliswa, her mother explained that they had received help from public health care for Zoliswa when she was "mad". They had been told that she was stressed, and she had been given injections and pills that made her better. The mother did not know what the medication was, or why it had helped. Similarly, in the case of Nomabali, the family had sought help for her both at the local clinic and at the hospital. She had been given various pills, but the family had not been told what was wrong with her or what the pills were for. It is important to bear in mind, however, that these are stories told from the perspective of the care receivers. It could be that the health providers from the public health care system had given an explanation and a diagnosis, but that it did not resonate with the belief system of the care receivers, or simply that it was not recalled or understood by the patients. As shown in Chapter 7.2, care providers and care receivers do not always share the same culture and belief system. Kittay and colleagues (2005) emphasise the importance of health providers' understanding the beliefs of their patients. In interviews with health providers it is evident that they have limited time to sit

with patients, get to know them and explain their own medical assumptions and explanatory frameworks to them. Providers of public health care in Madwaleni operate under extremely difficult work conditions, with too many patients, shortage of staff, limited equipment and medication. Adding to this many of the health workers do not speak the same language as their patients, and interpretation is limited, usually restricted to local nurses or family members. The result may be that important communication and information is lost in translation (Kirmayer & Swartz, 2014).

While family care tends to be individualised and specific to the patient, scientific health institutions provide, broadly speaking, standardised care (Tronto, 2010). The standardisation has largely been developed in the West, and this raises the question of its contextual fit in other settings (Mills, 2014). What has been termed "the politics of sameness" – a politics which does not take group differences into account, has been said to perpetuate and exacerbate disadvantage (Kittay et al., 2005; Shakespeare, 2014). This politics, which stems from notions of equal treatment, is operationalised in scientific health care in Madwaleni. By contrast, Kittay et al. (2005) argue that it is important not to assume that all people have the same needs, interests and situations; it is important to consider structural, social and individual differences. A politics of difference has been called for to replace the politics of sameness, in an attempt to address inequalities (Kittay et al., 2005). The data presented in this dissertation emphasise what has been found in other studies, that there are some commonalities in the experience and expression of psychosocial disability across the world (Cohen et al., 2014). There is also evidence to suggest that some symptoms of psychosocial disability can be effectively treated with scientific medicine. However, there are major differences in the understanding and conceptualisation, as described in Chapter 7.2. That is not to say that scientific health care is not relevant in the context of Madwaleni. On the contrary, in some cases it will be the most appropriate approach to care. But, it is crucial to also consider other available approaches to care instead of, or in addition to, scientific health care. This is the case both because for some people a range of healing options may be more appropriate, and because scientific health care alone does not have the resource capacity to care for all the people who are in need of care.

In the field of global mental health, community based mental health services have been called for (Cohen et al., 2014). These are largely unavailable in Madwaleni. Both public health personnel and case study informants expressed a wish for more community and home based services. In line with this, task-shifting and task sharing in the field of mental health has also been called for in the literature. There is a structure in Madwaleni for using unskilled or semi-skilled health workers, but for optimal task-shifting and task sharing there has to be adequate compensation, training and supervision (Petersen, Fairall, et al., 2014; Petersen, Lund, et al., 2012). Based on interviews with unskilled, semi-skilled and skilled health workers in

Madwaleni, all of these areas are lacking. In the context of communities like Madwaleni one must also be mindful of already challenging conditions for health workers, and the potential burden that task-shifting and task sharing may pose to them.

Traditional healing

In addition to, or sometimes instead of public health care, people in Madwaleni utilise a variety of traditional healing practices in the care of mental disorders. These are practices broadly described as the folk sector by Kleinman and Helman (Helman, 2007; Kleinman, 1980). This dissertation does not do justice to the complexity of traditional healing systems in Madwaleni, and it is outside the scope to explore these in detail. The aim is to explore the complex terrain in which people in Madwaleni navigate in order to seek and provide care to people with psychosocial disabilities.

It was said by a nurse at the hospital that in the past people in the area associated all illnesses with witchcraft, and thus primarily sought help from traditional healers. Over time, however, people have learned more and more about scientific medicine, and now use it and trust it much more. Despite this, traditional healing remains influential in Madwaleni, and there are several reasons why this may be so. Xhosa culture and traditions are embedded in the belief system of the traditional healers. As described in Chapter 7.2.3 people in Madwaleni commonly associate mental disorders with spiritual and supernatural forces. It is believed that this can only be treated and cured by healers who have the skill to communicate with these forces, and have appropriate treatment and medication for this. Public health services are thought to be inappropriate to care for or cure illnesses attributed to such forces. Nevertheless, the traditional healers often tell patients to continue with treatment from scientific medicine alongside the traditional healing. They emphasise that both in traditional and public health care, compliance is key to healing.

Another reason why people seek care from traditional healers may be that they are more available. There are many healers, located within the communities, usually a short walking distance from any household. While people speak of long distances to travel and long waits at public health facilities, traditional healers are close by, they see patients immediately, and they have time to interact with their patients.

Financial care

Care in Madwaleni can also be found in the form of financial support, such as disability grants or shared income within or between immediate or extended households. Disability grants and other social grants provide essential financial care to most households in Madwaleni. Most households in this study survive primarily on the various grants offered to people in the household, such as child support grants, old age pensions and disability grans. The grants are

offered by the government as a strategy to combat poverty (Statistics South Africa, 2014; Surender et al., 2007).

Another example of financial care in the case studies is in the case of Nomabali. Nomabali's daughter and granddaughter have left the day-to-day and hands-on care of Nomabali to the great-granddaughter Vuyelwa. This is so that they can travel to places where they can work and earn an income for the entire household. Adding to this, the immediate household where Nomabali lives also receive financial support from members of their extended household.

Emotional care

The most common care written about in the literature and spoken about by the informants in this study is the practical care; supporting people to seek care, financial support, support carrying out activities, and so on. There is also another essential aspect of care and that is emotional care. Concerning emotional care, I was told repeatedly that people in Madwaleni specifically, and isiXhosa speaking people more generally, do not have a tradition for talking, sharing emotions, crying in public and talking about problems. Even at funerals people do not usually cry and draw attention to their own sadness. They are worried that other people will also start crying as a result. A reverend expressed worry at this, as he believed that people might get depressed if they do not cry and deal with their sorrow.

The importance of emotional support was emphasised by Khaya, who had received support from his church which was essential for his healing and coping with his mental disorder and his family problems. As a church leader himself now, he encourages people to cry and speak about their problems and their feelings, and to pray. But he also emphasised that one should not speak to too many people about these issues, as one "might lose part of yourself, sharing with too many."

Khaya also described how his happiness today is linked to his being loved and cared for by his second wife, and in return, he cares for her as well, and their children. They care for each other in multiple ways: financially, cooking, cleaning, loving each other and supporting each other. They support each other's individual development, as well as the family's collective development. With this care, they both prosper and flourish, which is of benefit to them as individuals, as a couple and to their whole family. For Khaya, the care he receives from his wife and the care he provides for his wife are important in determining his mental health. He describes how the caring relationship with his wife has been essential in improving his mental health.

Occupational support

Care in its broadest sense has been said to be about meeting the needs of ourselves and others (Fisher & Tronto, 1990; Sander-Staudt, 2011). In the case studies, several of the people with psychosocial disabilities receive support carrying out their occupational activities, such as self-care, household chores, providing income to the household and so on. Some are dependent on this support for their own survival, others are deprived of their occupations, when perhaps it could have been better for them to be assisted in doing them. Care is not just about giving care, but also about receiving care, and allowing other people to give care (Tronto, 1993), which is also about meaningful occupational participation (Reed et al., 2010). This perspective is exemplified in the case of Khaya, described above, and the reciprocal nature of the care he gives to (meaningful occupation) and receives from his wife.

Pumla is one of the participants in this study who has been deprived of the opportunity to provide any form of care herself. She has had the occupations of caring taken away from her, which in turn may reduce her sense of purpose and meaning (Kittay et al., 2005; Reed et al., 2010). With what, I suspect, are the very best intentions, Pumla's family have "relieved" her of most of her chores and duties, believing that what is best for her is that they do them for her, and that she is left alone. In reality, however, they may be contributing to restricting her meaningful participation and thus her opportunity to flourish and prosper (Engster, 2005; Kittay et al., 2005; Pereira & Whiteford, 2013; Whiteford, 2000). Indeed, Kittay and colleagues (2005) argues that good care is about providing care when it is needed, and refrain from providing care that interferes with people's freedom to exercise their capabilities and their own agency (Kittay et al., 2005).

The occupational therapy department at the hospital said that they do sometimes get involved with the care of patients with psychosocial disabilities. They primarily assist the family in handling the situation; making sure the patient has a full time carer in the family or household, advice on medication and on getting a disability grant. They do not offer advice on how to make sure that the patient is included and participate to his or her fullest ability. The opportunity to participate as fully as possible is both a disability rights and an occupational justice issue.

Church support

In Madwaleni many people find support and ways of coping through their faith in God, and confidence that he provides the necessary care. People also find support through prayer or the preaching of gospel. Adding to this, churches also provide support beyond the obvious support religious people find through their faith. Churches provide support for people who suffer from mental disorder, and they promote mental health issues through various church societies and groups where people can talk, share experiences and help each other. In the

groups, they organise various forms of training, education, counselling or social activities. The groups are important support systems for many people, and can be crucial for prevention of mental problems and in the care for people suffering from mental disorders. If they see that someone requires help that the church cannot provide, they advise people to seek help from other care sectors, such as clinics or hospital. This is dependent on their ability to recognise mental disorders, and see mental health problems as something that requires treatment from public health care. The care provided in churches, through the different church groups, can play a crucial role in sustaining good mental health, in promoting optimal mental health and preventing mental disorder. The churches promote healthy, reciprocal relationships through their church groups, teaching people to both receive and provide care.

Care for the carer

In most of the case studies we see that the households experience what is described as double-trouble of caring, related to the general caring of the household, and caring for the special needs of the person with the psychosocial disability (Sandy et al., 2013). For some, the care burden is enormous. For instance, for Vuyelwa, Nomabali's great-granddaughter. Vuyelwa had to discontinue her education and put her own life and her dreams on hold in order to contribute to the care of the overall household and the care of her grandmother. Nomabali used to be one of the major care givers in the household, but since she became ill, she has become a care receiver, placing a major burden on other household members.

In order for a carer to provide care for someone else, someone has to care for the carer, to relieve care giver burdens, and ensure appropriate care for the care provider (Viana et al., 2013). This aspect of care is often overlooked. Within scientific health care, care providers receive training, support and compensation. One may question the quality and appropriateness of all of these, but at least there is a system in place to care for the carers. In many African communities, however, the main care givers are families or household members (Breen et al., 2007; Evans & Thomas, 2009). In community, household and family care, care givers are largely on their own, as the case studies presented here also illustrate. Financially, one may argue that there is some support through the government grant system.

While care is sometimes thought of as a reciprocal activity, the care receiver is not always able to care for the care giver, and thus care for the carer often has to be carried out by a third party (Kittay et al., 2005), or the carer must care for him or herself (Engster, 2005). Informal care givers are of invaluable importance in Madwaleni, where the formal health system faces such enormous constraints. Thus, caring for the carer should be seen as of utmost importance in order to strengthen and sustain structures of care. It is essential to provide care givers with the necessary support, compensation and training (WHO, 2002).

7.3.2 Care providers

It is widely argued that the need for and provision of care is dependent on social and political organisation, on individual needs as well as cultural, ethical, contextual, economic and political circumstances (Kittay et al., 2005; Tronto, 1993). In the global mental health literature, care providers are mostly described as scientific health care providers or traditional health care providers. This dissertation finds that in the six case studies, care is much broader, and more in line with Tronto's definition of care, as something that is both private and public, which happens at all levels of society; in the household, in the community, in governments, in institutions and so on (Tronto, 2001). At the core, care is an intimate relationship between two or more people, which affects everyone involved (Kittay et al., 2005). Ethics of care is closely related to Ubuntu (Kittay et al., 2005), and both are highly relevant in the exploration of care in the context of Madwaleni. Below I will outline the various care providers I have come across during my fieldwork in Madwaleni.

Government

A major care provider in Madwaleni is the government. The government is responsible for the provision of public (scientific) health care and for providing government grants. The lack of priority for comprehensive mental health at policy level in South Africa (Marais & Petersen, 2015; Petersen, Lund et al., 2012) is reflected in the inadequate provision of mental health services in the public health care system in Madwaleni. Adding to this many of the skilled health workers are from a different culture and speak a different language than the patients, and along with the transient nature of many of the professional health workers, this may compromise the compliance of the patients and the continuity of care (Kirmayer & Swartz, 2014; Kittay et al., 2005).

Many of the nurses at public health care facilities in Madwaleni, however, are from the local community, but they are trained in scientific medicine. This places them culturally both as part of the public health care system, and as part of the culture of the local community. We see this complexity exemplified in several of the case studies, with nurses encouraging patients to seek help from traditional healers in addition to the help they receive from public health care. This could be linked to the health worker's lack of skill, confidence and capacity to manage mental disorder. Or it may be because of the health worker's holistic attitude towards collaborative practice between the two sectors. There is, however, no formal mechanism to bridge these two systems of care.

Traditional healers

Traditional healers are considered to be the backbone of African communities, and remain highly influential, especially in rural areas like Madwaleni (Cumes, 2013; Peltzer, 2009).

Traditional healers are part of what Kleinman and Helman refer to as the folk sector, consisting of healers and diviners of various kind (Helman, 2007; Kleinman, 1980). Historically this was the only sector of care available in Madwaleni, outside the various forms of family and community care. In Madwaleni the traditional healers speak the same language and share the culture of their patients. Furthermore, they are often from the same community, and have built up a relationship of trust and familiarity in the community. Apart from Simkite and Nomabali, all the case study informants had sought care from traditional healers for their mental health problems. Some healers had said that they could not help, and had told them to seek care from the hospital. For instance, in Khaya's case, the first healer he went to suggested that he seek care from the hospital instead. At a later stage, however, a Ghanaian doctor at a tertiary hospital suggested that Khaya seek help from a traditional healer, as he thought that perhaps Khaya had been bewitched. In Zoliswa's case they had sought help from various different traditional healers, but none of them had helped. In other case studies, such as Pumla, Thamsile and Aseko, their experience was that the traditional healers had helped a bit, but not cured them completely.

Household

In traditional healing, individual patients are not seen as isolated, but part of a group, and thus involvement of people from this group is essential for healing and care (Berg, 2003). Janzen (1978) refers to this as a therapy management group (Janzen, 1978), while Kleinman and Helman call it the popular sector (Helman, 2007; Kleinman, 1980). In most African communities, including Madwaleni, the majority of this sector is made up of immediate and extended households. I would argue that households make up the most important care provider in Madwaleni, as I have seen similarly in other African communities (Braathen et al., 2016). Despite this, the popular sector is the sector that receives the least acknowledgement and attention in research and development.

Most care starts at household level, where initial care is provided and care decisions are made (Kleinman, 1980). Care in the broadest sense is an activity that most members of a household takes part in. In a household, each household member may have a care responsibility, where the overall or ultimate goal is for the household unit to survive and be well. Care choices are made within a household unit, an extended household unit, or even with influence and help from the community surrounding the household. A person can be both a care receiver and a care giver at the same time, or at different times throughout life. For instance, in the case of Nomabali, the various members of the household, immediate and extended, have different care responsibilities. While it is Nomabali's great-granddaughter, Vuyelwa, who has the day-to-day responsibility of the household and the care for Nomabali as head of the household, Vuyelwa's mother and grandmother provide care through the provision of income to the

household, working a few hours away from Madwaleni. Nomabali's daughter-in-law, Vuyelwa's aunt, also helps to care for Nomabali. In the absence of Vuyelwa's mother and grandmother, and with the great-grandmother, Nomabali, being sick, Vuyelwa is the head of the household. As a result, she has had to drop out of school to tend to her care duties.

Care is often seen as a woman's domain (Sander-Staudt, 2011; Tronto, 1993, 2001). While this is true in the case of Nomabali, described above, the reason for this is that most of the men in the immediate and extended household had passed away. From a broad perspective of care, as described by Tronto (Tronto, 1993), care is both women's and men's domain. It is also both an adult and a children's domain, as most, if not all, members of a household somehow contribute to the care of the household and its members.

One hears about assumptions of lack of care, of neglect and ill-treatment. The reality is that looking closely at the case studies we see that it is more a matter of survival and doing the best that they can within their means, possibilities and knowledge. The case studies emphasise that overall care choices are a matter of practical decision-making, based on the few choices available for a household, with the overall aim of survival for the household. Optimal care becomes secondary, if that, to survival. Similar patterns have been found in studies from other parts of South Africa, where competing care demands within families and households compromise the quality of care and the livelihood and well-being of the family and overall household (Breen et al., 2007a; Duncan et al., 2011a, 2011b).

Health providers in the public health system generally have the impression that family and community support systems are good in Madwaleni. Their experience is that patients are cared for at home, and get help seeking care outside the home. Most people come to the health facilities with a person assisting them. Their impression is that families genuinely want to help and care for their sick family members as best as they can. Some attribute this to the Ubuntu nature of the culture of the people. It is important to consider, however, that there may be both positive and negative aspects to the culture of Ubuntu. While it is generally presented as a positive and inclusive philosophy in the literature, Goodley and Swartz (2016, in press) question this uncritical presentation. In the interdependent and collective nature of Ubuntu follows obligations and responsibilities in terms of who is obliged to carry out certain care activities. In the case of Nomabali, for instance, we see that her great-granddaughter Vuyelwa has the obligation to be the main carer for the household in general and her great-grandmother in particular, and this has enormous negative implications for her own life and her dreams.

Community

The culture in Madwaleni is communal in nature, with a strong sense of interdependence. In the context of care, this plays a central role, and can potentially be integrated into the overall

care system, and thus contribute even more in the delivery of care activities. However, this requires careful consideration of structures of compensation and support for both care givers and care receivers. It also requires consideration for the potential positive and negative aspects of the Ubuntu nature of the culture, as well as the potential consequences of moving away from interdependence towards independence.

Church

Churches and various church groups also play a role towards caring for people with psychosocial disabilities. Moreover, churches are one of the few care providers who directly or indirectly work towards mental health promotion and prevention of mental disorder. Church structures and representatives as care providers are rarely included in official mental health programmes or research. The results from this study indicate that church structures could or perhaps should be seen as part of a larger care picture, and contribute to relieve the enormous care burdens placed primarily on the public health care system and on households.

7.3.3 Pluralism of care

A number of studies from South Africa support the argument for medical pluralism. This could be through increased collaboration between different health services, between different government sectors and NGOs, and even between public and traditional health services (Brooke-Sumner et al., 2016; Grimsrud et al., 2009; Sorsdahl et al., 2010). In the care for people with psychosocial disabilities in Madwaleni, however, there is more than medical pluralism; there is a broad pluralism of care, as I have illustrated in the previous sections of this chapter. All the sectors of care described by Kleinman, Helman and Janzen (Helman, 2007; Janzen, 1978; Kleinman, 1980) are involved. Janzen (Janzen, 1978) talks about four therapeutic systems, while Kleinman (Kleinman, 1980) and Helman (Helman, 2007) speak of three sectors of care. The systems they describe, however, are similar, consisting of healers from the more spiritual sectors, referred to as the folk sector by Kleinman, and healers from scientific medicine, referred to as the professional sector by Kleinman. Kleinman also acknowledges the popular sector, consisting of family and community care, as an essential sector of care. Janzen refers to this sector as a therapy management group, which play a crucial role in help-seeking and treatment adherence in the other care sectors. Based on the evidence presented in this dissertation, however, I argue that care is even broader than these sectors of care, and more in line with the description of care in the ethics of care literature (Engster, 2005; Kittay et al., 2005; Tronto, 1993).

Despite all the potential strategies and providers to care for people with psychosocial disabilities, the gap between the need for care and the provision of care is large, and the consequence for people with psychosocial disabilities, their families and households is

detrimental, as the case studies illustrate. There are multiple challenges at the interplay between the various sectors of care. While there is broad acceptance of the pluralistic care system present in most African communities, there is little evidence of and attention addressing the overlap between the various sectors, and how they can best be bridged. Various systems of care can coexist successfully, but there are often tensions, and collaboration is often challenging (Peltzer, 2009). As patients throughout South Africa, including Madwaleni, commonly use the different sectors of care simultaneously, however, a collaboration is necessary (Campbell-Hall et al., 2010; Mzimkulu & Simbayi, 2006; Ross, 2008).

There are many challenges for cross-referral across care systems. From a public health care perspective, there is a need for greater mental health literacy, for both community members and for professional and other health personnel. However, it is also crucial, if limited resources are to be used optimally, that outcome evaluations of treatments within and across the full range of health care sectors are conducted. It is unlikely that there will be an abundance of mental health specialists in Madwaleni or similar contexts any time in the near future. Thus while public health care may still, for many, be the ideal treatment option, this is not a likely solution to the problem in Madwaleni in the near future. Within the global health and mental health literature, there is currently a great emphasis on what has been termed "task-shifting", which is the deployment of lower-level health providers or lay health workers to provide basic prevention and treatment services, supervised by more skilled health workers at secondary or tertiary level (Saraceno et al., 2007; Thornicroft, 2007). This may well be an option in contexts like Madwaleni. However, in task-shifting one must be mindful of the already challenging conditions health workers and others work under.

Given the strong link between physical and mental health conditions (Leucht et al., 2007; Prince et al., 2007), an interdisciplinary approach should be employed. For instance, there is already a rehabilitation team in Madwaleni, but these are currently not involved in the treatment or prevention of mental disorder. A more difficult question, but one that needs to be addressed, is how to integrate different forms of healing (including indigenous or spiritual healers) in evaluated innovations in task-shifting.

Madwaleni has pluralism of care. While the introduction of biomedicine is relatively new, especially the introduction of primary health care to the area, traditional medicine, has a long history in Madwaleni. Also structures of family, household and community care are deeply rooted in the African philosophy of Ubuntu, highly prevalent in the community. In Madwaleni the traditional healers have supported the transition of the population into accepting scientific medicine. Adding to this, there are traditional healers on the hospital board. These are all efforts that have been made to bridge the traditional healing sector and public health care

sector. However, intersectoral and other cooperation was said to be difficult by many of the health providers, not just between the folk sector and the professional sector, but also within the popular sector. Lack of staff was cited as a major reason for this, and the way the health system is organised, falling under different health departments and municipalities. Adding to this, lack of a central data system makes collaboration challenging, as they have very little knowledge of what has happened to a patient before. Information should be in the patient's health books, but many have lost them, or forgotten to bring them. As a result, people end up moving around in the referral system, with very little continuity of care.

A pluralistic care system is complex, and many care providers ascribe to various care systems simultaneously. For instance, the reverend at the Presbyterian Church of Africa who said that at his church the care for a sick person would be a combination of praying for him or her, referring them to the doctor and sometimes to a Zionist for exorcism. This seemed to be especially the case for people suffering from mental disorders, as their symptoms are often associated with both biomedical problems and with witchcraft. Similarly, the nurse who cared for Pumla at the hospital provided her with hospital care and at the same time told her to seek help from a traditional healer. Nurses at the hospital and clinics in contexts like Madwaleni have been said to hold a unique position as the link between various care systems (Kahn & Kelly, 2001), but in the context of Madwaleni their position is not utilised to its full potential.

There is an informal referral system in place between many traditional healers and public health care. Traditional healers said that they often tell patients to combine the care they provide with care from the hospital or clinics. They believe that some conditions need treatment that is only available at the hospital, while other conditions can only be treated by the healers. They feel, however, that the collaboration with public health care is only one way, and that the hospital and clinics do not have respect for the healing practices of the traditional healers. And indeed, most public health care providers said that they do not refer patients to traditional healers, but they also do not tell them not to seek help from them, as long as the patients comply with the treatment from scientific medicine. Research from South Africa has shown that if there is a conflict, the folk system is often relegated as the subordinate care system (Kahn & Kelly, 2001). In the case of Pumla, she was referred from public health care to a traditional healer, but there was no mechanism to bridge the different health care contexts for Pumla and her family, and no follow-up. It appears that this is not a collaboration as such between the sectors, but the sending of a patient to traditional healing at least partly because of the health system challenges within the public health care sector.

7.4 Access to care for people with psychosocial disabilities in Madwaleni

In LMICs, including South Africa, there is a lack of priority for mental health at policy level, lack of equipment, personnel, medication and low mental health literacy. As a result, the majority of people with mental disorders are not diagnosed or treated (Marais & Petersen, 2015; Petersen, Lund et al., 2012; WHO, 2015). In South Africa and other LMICs, the gap between the need for mental health services and available services is critical. Care needs are expected to increase, while care resources remain low (WHO, 2002). The Eastern Cape is one of the most under resourced provinces in South Africa (Lund, Kleintjes et al., 2010). In a just society, however, individual care needs should be met within the constraints of available resources (Kittay et al., 2005).

Accessibility to health care has been said to encompass four key components: Accessibility, availability, acceptability and quality (UN, 2000). While these are developed to explore and understand access to scientific health care, they are also relevant for other care options. I will explore these components in relation to access to care for people with psychosocial disabilities in Madwaleni.

7.4.1 Accessibility

Accessibility is referring to non-discrimination, physical accessibility, economic accessibility and information accessibility (UN, 2000).

On the aspect of discrimination, most care options seem to be available to people without discrimination. However, people may feel ashamed when they themselves or someone close to them experience symptoms of mental disorder, and this may prevent them from seeking care. For instance, Khaya, who tried to hide his symptoms, as he was worried about people's reactions. However, when people do seek care from their families, churches, traditional healers or public health care, they are generally accepted. Concerning disability grants, however, among all the case studies it was only Zoliswa who received a disability grant because of her psychosocial disability. I would argue that several more would and should qualify. The reason why people had not applied for or had not been offered disability grants could be related to people not seeing mental disorder as a disability, as described in Chapter 7.2.1. Thus, they are not considered appropriate recipients of this grant. Based on several of the case studies, however, I would argue that many people with psychosocial disabilities have activity limitations and participation restrictions, and thus qualify for a disability grant.

Concerning physical accessibility, this is composed of getting to, from and between facilities, and getting around at the actual facilities. The clinics, health centre and hospital are spread out in Madwaleni, but the facilities are located along major roads, often far away from the communities where people live, as most traditional healers and churches are. This makes access to public health care more difficult. For people in the community, as exemplified in several of the case studies, getting to public health facilities is challenging. The distance in kilometres in this area are not large, but the terrain is challenging and the condition of the roads and paths is bad, making hospitals, clinics and health centres inaccessible for large parts of the year. Weather conditions add to the terrain problems, with heavy rains, flooding rivers and muddy and slippery roads. Because of the poor condition of the roads, public transport is unreliable at best, and sometimes completely inaccessible. Traditional healers are numerous, located within the communities, and are usually within walking distance. They are thus more accessible.

There is a lack of vehicles and ambulances for emergencies and referrals between public health care facilities. This places limitations on outreach services from hospital to clinics, and from clinics or hospital to communities or homes. Community based services are generally restricted to unskilled or semi-skilled community health workers, and their only mode of getting around is by foot.

Many of the case study informants told stories of being referred back and forth in the public health care system. For instance, starting at the clinic, on to the hospital, from the hospital and back to the clinic or in a few cases referred on to tertiary care in Mthatha, back to the hospital or the clinic, and so on and so on. People go back and forth, spend money and time, and with very little result or help gained in the process. In some cases, this has been their health care routine for years, but their problems remain the same. The process is demanding for the person with psychosocial disability, for their family and immediate and extended household. It is time consuming, costly and frustrating.

On the aspect of economic accessibility, public health care is on paper free, while traditional healers generally charge a fee for their services. In reality, we see that for most people there are still more costs involved with seeking public health care compared to seeking traditional health care. The population of Madwaleni is poor. As mentioned above, most people have to travel long distances to visit clinics, health centre or hospital. Transport is expensive for many, especially people who require assistance to move around, as they have to pay for two people or more. The further they travel, the more they pay for transport. When the quickest road is flooded transport costs increase, as they have to travel a detour to get to the facility. Furthermore, public transport stops when the sun sets, usually around 5pm. Patients at the

hospital and clinics are sometimes not seen before 5pm on the day they have an appointment, and they have to either sleep at the health facility overnight, or they have to miss their appointment, and come back to the facility on another day. Even if patients are lining up at the facility early in the morning, before the facility opens, they are sometimes not seen on the day of their appointment. This results in their being away from income-generating activities, and thus contributes to loss of income to the household. Adding to this, while primary health care is free, some hospital services are not. At the end of the day, it often ends up being cheaper for people to pay a small fee to the traditional healer, as they save the transport money, and care seeking is quicker, and thus results in less loss of income.

Information accessibility in the area of psychosocial disability is more or less absent in the context of Madwaleni. The knowledge and awareness of mental health and mental disorder is lacking at public health care facilities, among traditional healers, as well as within families, households and communities. From the data material presented in this dissertation, it seems that the highest mental health awareness can be found in churches, where promotion and prevention of mental ill-health is on the agenda, either directly or indirectly.

Health services for mental disorders are said to be minimal in Madwaleni. No one has the primary responsibility for this patient group, no one advocates for them, and as a result no one pays much attention to them. Adding to this, they do not advocate for themselves, as they often do not perceive of themselves as having a mental disorder.

7.4.2 Availability

Availability refers to the quantity of services available (UN, 2000). In the context of Madwaleni some care options are more available than in other parts of the world. For instance, family, household and community care. The African philosophy of Ubuntu is at the core of the culture of this community, and care responsibilities are strongly connected to the communal nature of the culture and the interconnectedness of the people. Adding to this, care structures such as traditional healing and church care are highly available and utilised by people in this community. Interestingly, these aspects of care for people with psychosocial disabilities are rarely included in research and/or development strategies. What is considered is the availability of public health care to provide for people with psychosocial disabilities, and from this perspective, availability is poor. It is widely accepted and acknowledged that most LMICs, including South Africa, face a shortage of specialised mental health personnel, facilities and treatment (Andersson et al., 2013; Lund, Kleintjes et al., 2010). This is also the case in Madwaleni. Public health facilities in Madwaleni experience a major lack of personnel, equipment, electricity, medication and transport. Staff are overworked and underpaid, with very little time with each patient. There is a high staff turnover, and the fact that health providers

are often not paid their salaries makes it unattractive for many skilled health workers to work in this context.

South Africa has seen a shift from institutionalisation of patients with psychosocial disabilities to care in the primary health care system. There are, however, major shortcomings in the primary health care system, as this study has also illustrated, and thus in practice in South Africa deinstitutionalisation has meant a shift to community and family care (Engelbrecht & Kasiram, 2012). There has been a call for more community based mental health services, for task-shifting and a move towards medical pluralism (Petersen, Lund, et al., 2012). Community health workers play an important role in the health care delivery in Madwaleni. They are the only public health workers who work in the local communities, and in people's homes. However, they receive very little compensation, and most see it as a stepping-stone to a higher paid position in the facility. Adding to this, most of the home based care is funded by an NGO. On this basis, one may question the sustainability of community health workers and home based care programmes. The lack of outreach and community based services in the area is a major barrier to effective mental health promotion, prevention and treatment.

Accurate diagnosis of mental disorders at public health facilities is difficult, due to lack of qualified personnel. People with severe mental disorders are often diagnosed with psychosis, which is used more as an umbrella term for a number of symptoms of mental disorder. Health providers said that they rarely diagnose people with common mental disorders such as depression, or more severe mental disorders such as schizophrenia or bipolar disorder. Patients with depression, for instance, are often not diagnosed with and treated for depression, but may be treated for the somatic symptoms like sleeplessness, loss of appetite, etc. One nurse said, "We don't treat them, we just cure the symptoms." At the hospital, people with severe mental disorders are often sedated, treated with anti-psychotic medication. There is no psychiatric ward, so they are admitted to the general ward, which can be problematic due to their behaviour. Thus, relatives are encouraged to stay with them. After 72 hours they are discharged if they have been calmed down with medication. If they are not more settled in their behaviour at this point, they are referred to a tertiary health facility in Mthatha.

7.4.3 Acceptability

Acceptability refers to culturally, contextually and individually appropriate services (UN, 2000). An important aspect of care is attentiveness; the ability to recognise a need for care and to respond to that need appropriately (Tronto, 1993). From that perspective, it is important to explore issues of mental health literacy in order to understand people's knowledge, beliefs and understandings. This forms the basis for recognising and responding to the need for care. I have discussed conceptualisations of psychosocial disability in Chapter 7.2 above. Studies

have found that mental health literacy is low among a large part of the South African population (Andersson et al., 2013; Keikelame & Swartz, 2013b; Seedat et al., 2009). Low perceived need for mental health services, closely linked to low mental health literacy, has been found to be a major barrier to initiating and continuing mental health treatment based on scientific medicine (Andrade et al., 2013; Hanlon, Luitel et al., 2014; Petersen, Ssebunnya, Bhana, & Baillie, 2011). Studies from South Africa have found low mental health service use, lowest among Black respondents and in Eastern Cape Province (Seedat et al., 2009). Low mental health literacy is generally taken to mean lack of knowledge of mental health from the perspective of psychiatry. From that perspective, one may argue that the different approaches to psychosocial disability described above are not acknowledged. The fact that people do not perceive of mental disorder from the perspective of psychiatry does not necessarily mean that they have low mental health literacy. From this study we see that people may recognise symptoms of mental disorder as they are described in for instance DSM IV, but they may not conceptualise of the symptoms within a psychiatric paradigm. In responding appropriately to care needs, one must take the broad range of conceptualisations for psychosocial disability into consideration. One must be careful not to assume that something is low mental health literacy, and examine if it may be issues of language or conceptualisation perceived of as lack of knowledge.

In the public health system in Madwaleni, many of the providers do not speak the same language as their patients, and there are no formal structures for interpretation available. They use family members or other health workers who speak the language for interpretation. The experience of many skilled health workers is that important messages often get lost in translation. Adding to this, many public health workers do not share the culture of the people they serve. Other care structures, such as traditional healers and churches are more culturally and contextually appropriate. People understand them and trust them, as they share the same culture and language.

In the global mental health literature, there is s call for community participation to scale up appropriate mental health services, contextually and culturally and to ensure ownership and awareness (Petersen, Baillie et al., 2012).

7.4.4 Quality

It is outside the scope of this dissertation to investigate and determine the quality of the different care options available in Madwaleni. There is, however, substantial evidence on innovative interventions for mental disorders that work in low-income contexts, but there is a lack of evidence on how to implement and scale-up these in real-life contexts. Key challenges to successful implementation of interventions in South Africa, including Eastern Cape

Province, is the lack of contextual and cultural appropriateness, adopted to local explanatory models for mental disorder, incorporating medical pluralism, training, supervision, support and compensation, diagnosis, help-seeking, and treatment adherence (Lund et al., 2012; Petersen, Fairall et al., 2014; Schierenbeck et al., 2013).

The satisfaction of the patients depends on the patients' awareness of their patients' rights and human rights. Most people in this area have very little awareness of this, and are happy with whatever they get, and thus complain very little. Health personnel wish patients were more aware, and could be better advocates for patients' rights, pushing health facilities, providers and in the end the government to provide better services.

7.5 Strengths and limitations of the study

Qualitative research findings, such as the ones presented in this dissertation, are not generalizable in nature (Holloway & Biley, 2011; Hollway & Jefferson, 2013). As such, inferences cannot be drawn from the data presented here, to be true for the entire population of Madwaleni, for Eastern Cape, for South Africa or for LMICs. However, studies from these contexts have highlighted a number of common challenges, which are also prevalent in the context of Madwaleni, but they often fail to account for individual stories and explain challenges experienced by individuals and households. Case study methodology, as utilised in this study, contributes to building an evidence base from the ground. The aim is to explore and understand individual stories and experiences of psychosocial disability, to analyse and understand the roles of culture and context in shaping experiences and behaviour. Case studies are useful for carrying out in-depth explorations of contemporary phenomena in their real life contexts. Interviewing several people in each case study gives multiple perspectives towards the same story (Crowe et al., 2011; Stake, 2006; Yin, 2013), and is also a very useful technique for ensuring the validity of a qualitative study.

Due to financial and time constraints, I was not able to follow up with the case studies over time to the extent that I would have liked to in order to study changes in their experiences and behaviour. Most of the informants I only met with once or twice, with the exception of Khaya and Nomabali who I followed up over a period of several weeks. Furthermore, in some of the cases there were other potential informants that I would have liked to interview, in order to shed more light on the particular case. For a variety of reasons this was not always possible. Some of the potential informants were away or unavailable during the time I was in the field, and I was not able to come back to do further interviews.

During my fieldwork in Madwaleni I used several different interpreters. For the most part interpretation did not pose a big challenge. However, some information may have been lost in

the process of translation, or may have been altered due to misunderstandings between the interviewer and the interpreter. To minimise the potential limitations of interpretation I made sure to spend time with the interpreters prior to data collection to inform and instruct them about the research project, the methods, interpretation and the roles of both myself as the researcher and of the interpreter. Prior to each interview I briefly talked about these roles again. After each interview we discussed major points and issues that had come up, confirming with the interpreter that I had understood correctly and clarifying any misunderstandings or confusions. While for the most part the interpreters were unknown to the informants, they shared both language and culture, and therefore I got the feeling that the interpreters contributed to putting the informants at ease and establishing trust between me, as a foreigner, and them. In a few of the interviews the interpreter and the informants knew each other, which I was aware could be an issue of ethical concern. In these interviews informed consent became an even more important process, especially explaining the roles of both myself and of the interpreter to the informants, as well as issues concerning anonymity and confidentiality of both myself and the interpreter. In these few interviews, however, I got the sense that the relationship between the informant and the interpreter contributed to increased trust and to put the informants at ease, resulting in very good in-depth interviews.

Translation of mental health terms can be difficult, and one may risk that a question posed in English ends up having a different meaning when it is translated into another language, in this case isiXhosa. To minimise translation errors I had Khaya, who translated in most of the case study interviews, write down his isiXhosa translation for some key mental health terms (see page 125). I also had the same terms translated, and Khaya's translations checked, by two separate isiXhosa speaking academics at Stellenbosch University. While there were a few differences in the translations, the general meaning of the terms were largely the same, which reassured me that his interpreted questions to the informants were more or less the same as the questions I wanted to ask. It is important to note, however, that this study is not looking at specific mental disorders, but rather at mental disorder more generally. Therefore, in a study of specific mental disorders, the translations may perhaps not be adequate.

Informants for this study were recruited and selected using both convenience sampling and purposeful sampling. The goal was to gain multiple perspectives, and thus maximum variation in the characteristics of informants was crucial. In addition to the sampling method, the method of identification and recruitment of informants affects the data. In this study several people were involved in identifying and recruiting the informants. Informants for the contextual study were identified through the health services, through local chiefs, through interviews with case study informants, through the local interpreters and so on. I found that the relevance of the identified informants was dependent on the understanding of the study of the person who

identified them. Khaya, both an interpreter and an informant to this study, identified several of the case study informants and some informants for the contextual study. His understanding of the research questions was very good, and so was his identification of relevant informants, including himself. Other people who helped me identify informants did not have the same understanding of my study, and recruited informants who were not relevant. The result was that some interviews were not included in the final dataset. While I recognise that the inclusion of one of the interpreters as an informant could have negative implications, I found that his contribution both as an interpreter and as an informant was invaluable to this study. He shared his story with me as an informant after he had worked for me successfully as an interpreter for several week, and his understanding of the study was, as mentioned previously, great. He knew very well the implications of being an informant, and he shared his story openly and willingly.

Ensuring the validity and reliability of any qualitative study is complex and challenging. Inevitably, the data is shaped by everyone involved in collecting, providing, analysing and presenting them, as outlined in chapters 4.6 and 4.7. I believe, however, that were someone else to go to the same study area with the same research questions, their findings would be in line with the findings presented in this dissertation. I have taken a number of steps to ensure the validity of this study. Most of the findings are confirmed by several informants and by previous research. In addition to this, in several of the data collections we were multiple researchers in the field together, and our findings, interpretations and preliminary analysis were shared amongst the group and discussed. This process was useful to bring out differing interpretations of the same phenomena, which can shape further data collection in order to shed light on issues that were unclear and interpreted differently. Adding to this, I discussed the interviews with the interpreters immediately after each interview. This was to ensure that I had understood everything correctly.

Overall, the findings of this limited dissertation add to or emphasise findings from previous studies.

Chapter Eight: Concluding reflections

In this chapter I will provide some concluding reflections, highlighting the main contributions this dissertation makes to new knowledge. Based on that I will make recommendations for care planning and practices for people with psychosocial disabilities in Madwaleni and recommendations for future research.

8.1 Contributions to new knowledge

The movement for global mental health has, over the past decade, highlighted the consequences of mental disorders, and the treatment gap experienced by people with mental disorders in LMICs. While there is ample evidence on effective treatment strategies for many mental disorders, there are a multitude of barriers to their successful implementation, particularly in LMICs. Barriers are found at all levels of the health system, from global policies through to local health care provision. This dissertation makes a contribution towards understanding local realities, and identifying barriers and facilitators to care for people with psychosocial disabilities in LMICs. The dissertation addresses the vast needs for care for people with psychosocial disabilities in LMICs from a broad perspective of care, bridging different professional and theoretical perspectives. The uniqueness of the dissertation are the approaches taken to psychosocial disability and care, which have individual, cultural and contextual characteristics at the core.

The disability approach to mental disorder is relatively new to this field of research and development, and this dissertation highlights the appropriateness of this approach in investigations and strategies for appropriate and optimal mental health care. From the disability perspective, meaningful and appropriate participation should be at the core of all care activities. The relevance of such an approach is highlighted in several of the case studies, where most of the care provided contributes to restricting the participation of the person with psychosocial disability, rather than assisting them to participate in meaningful occupations to their full potential. In the context of Madwaleni, health care strategies for people with psychosocial disabilities are largely pacifying, offering people medication to relieve acute symptoms of mental disorder. In the case studies we see that care at household level is also pacifying, primarily towards ensuring the person receives some form of health care, complies with the medication and treatment prescribed by the health providers, and is relieved from his or her duties at home and in the community. There is ample evidence documenting that meaningful participation contributes to improved mental health. Thus, we need to rethink how we deliver mental health services, moving away from care as pacifying, to care as activating. Adding to this, the role of culture in mental health must be taken seriously and be at the core of any

mental health intervention. Culture, and the way people conceptualise health and illness is at the core of decisions made regarding treatment and care. That is not to say that a scientific, psychiatric approach is not relevant. As shown in this and many other empirical studies, there are many universal characteristics to mental disorders. As such, a combination of a disability approach to mental disorder and a psychiatric approach, taking into account cultural and contextual realities, would be the most appropriate.

The key challenge is not about carrying out studies that identify universal characteristics for good and appropriate care, but rather about developing methods for exploration of care needs and care resources which have individual, contextual and cultural realities at the core. The main weakness of the ethics of care literature in this context is its relative lack of explicit attention to these aspects of care. While the literature makes reference to the importance of culture and context, few studies in this field have been carried out with this at the core. There is a general lack of evidence on the cultural, contextual and individual nature of care needs and care provision.

The dissertation highlights the need for a broader approach to care than what we have seen in most of the literature so far. There is a lack of studies and interventions focussing on inter-sectoral approaches to mental health care, such as the role of alternative treatment forms or other community resources in prevention and care of mental disorder. While the research and development agenda has primarily prioritised strategies using scientific health care as a starting point, this dissertation argues for an approach to care that goes beyond that, exploring care structures at individual, family, household, community and government levels. This dissertation finds that in the context of psychosocial disability in Madwaleni, care is much broader than health care, and about much more than curing illness or looking after someone who is ill or dependent. The literature on mental health care in LMICs primarily has the perspective of care delivered in the professional, scientific medicine sector, or as an extension of this sector, such as community based mental health services. I argue for a broader approach to medical pluralism towards pluralism of care, including a wider range of care approaches using community and social structures, including the scientific and traditional system of care, as well as family, household and community care structures, churches, as well as the government social, health and welfare systems. The issues faced by people with psychosocial disabilities are complex and interlinked, and must thus be approached in an integrated and multidisciplinary way.

Care must be integrated into real-world settings, taking into consideration underutilised community structures that can be used in the promotion, prevention and treatment of mental health issues. For instance, the churches play an important role in Madwaleni towards

promoting good mental health and preventing mental disorders. The churches could also play a larger role in the identification and treatment of people with mental disorder.

The largest and most important structure for care at community level are the households, immediate and extended. The potential for using families, households and communities is underutilised in the context of Madwaleni. While they are strongly involved, they could be used much more actively and purposively both in the promotion of good mental health and prevention of mental disorder in general, as well as in the treatment and care for people with psychosocial disabilities. In the literature on medical or care pluralism there is a lack of acknowledgement for and attention to this care sector, by far the largest of the three care sectors described by Kleinman (1980).

For these resources to be utilised to their full potential, however, structures of support and collaboration must be explored, expanded and strengthened. For the family, household and community carers this could be in the form of mental health education and awareness, emotional, practical and financial support, and support and information about how to provide the best possible care.

There is very limited evidence on the effect of traditional healing practices towards preventing, improving or treating mental disorders. There is also little evidence on potentials for collaboration and referral between the professional health care system and the folk system. Some studies have looked at this collaboration, but there is a lack of evidence on ways of bridging these two systems in real and fruitful collaboration.

As identified by the global mental health field, there is a need to shift the focus of mental health care from cure to promotion and prevention, using an interdisciplinary team of lay and trained carers and care structures from the professional, folk and popular sectors. This strategy needs to be complemented by other strategies, for example, integrating mental health into other projects focussing on sustainable livelihoods and development of infrastructure. The challenges are complex, as this small study shows, but it is only by looking closely at local conditions that it is possible to develop culturally and contextually appropriate interventions and make optimal use of local resources.

8.2 Recommendations for policy and practice

While it was not the aim of this limited qualitative study to make policy recommendations, I will highlight some key issues and recommendations that may be of relevance for future planning and practice. The recommendations are towards the care for people with psychosocial disabilities in Madwaleni, but they may also be of relevance to similar low-income and low resource contexts in South Africa specifically and LMICs in general. As highlighted in chapter

seven and in chapter 8.1 above, many findings in this study are in line with findings from other studies from LMICs. As such, the recommendations made will also be relevant for policy and practice in other low-income and low-resource contexts. The recommendations I make here, however, are based on the findings from this dissertation.

- There is a need to shift the focus of care from care as pacifying to care as activating.
- Care for people with psychosocial disabilities is not just cure and treatment, but also prevention and promotion of mental health.
- In line with recent recommendations in the field of global mental health, I believe that in order to prevent, respond to and cure mental disorders a pluralistic and holistic approach to care is the most appropriate. An approach that has participation at the core, using a combination of scientific medicine, community based approaches and traditional health providers, as well as structures outside the traditional and public health care system, including religious societies, NGOs, immediate and extended families and households, the broader community, and so on.
- The findings presented in this dissertation are in line with the call for a move towards more community based mental health services (CBMHS), which should include social and rehabilitation services, in addition to medication. Adding to that, this dissertation highlights the need for an even broader approach to CBMHS, which includes the family, household, traditional healers, churches and other potentially relevant community structures and individuals. This broad approach to care could relieve some of the burdens of a pressed health system, but would require training and support at all levels.
- Care must have cultural, contextual and individual realities at the core
- Care for people with psychosocial disabilities is much more than public mental health care based on scientific medicine. There are multiple other resources at health system and community level that could and should be involved in care strategies. This requires a system of care also for the carers, which includes training, support and supervision. It also requires collaborative systems of referral and follow-up that takes into account the strengths and weaknesses of all the care providers.
- Family and household care is an essential form of care, but to ensure that this form of care is optimal and used to its full potential there is a need for support for the both the care givers and the care receivers.

8.3 Recommendations for future research

The movement for global mental health has identified a number of gaps in research, and many of those gaps have also been identified in this study. I will not repeat all the gaps identified in

the literature, but will highlight the most important gaps in research and suggestions for future research in the context of Madwaleni.

- There is a need for more research and strategies for promotion and prevention of psychosocial disabilities, in addition to the research on causes, treatment and cure of mental disorders.
- There is a need for studies exploring the relevance and effect of traditional healing practices in preventing, improving, diagnosing and treating mental health issues and disorders.
- There is a need for studies exploring integration and collaboration between various actors and providers within a pluralistic care system including all potential care providers from a broad perspective of care as outlined in this dissertation.
- There is a need for research on different cultural, traditional and knowledge systems, through a process of dialogue and co-learning between these different systems. To achieve this there is a need for more bottom-up strategies, listening to diverse local needs in combination with already developed and tested best-practices. Exploring cultural feasibility and acceptability of available interventions, strategies and practices.
- There is a need for evidence on risk factors for and experiences of mental disorder across cultural settings.

This dissertation was small in scale (though embedded in a much larger study). However, a focus on the detail of people's lives reveals a picture more complex than may appear in larger studies. Clearly, there is a complementarity between work which focusses on depth (such as ethnographic work and case studies), and work which focusses on breadth (including large-scale surveys). At a time when more narrowly focussed qualitative work is commonly eschewed in favour of larger-scale studies, I believe I have given an example which demonstrates the value of narrowing the focus and paying keen and close attention to context, not as an alternative to broader scale research but as a partner with it. We need the big picture, but to move the field forward and to change people's lives, we need to understand and engage with detail as well.

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Appendices

Appendix A

Ethical approval for EquitAble project

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

15 March 2010

MAILED

Prof L Swartz
Dep Of Psychology
Stellenbosch University
Main Campus
Stellenbosch

Dear Prof Swartz

"Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa."

ETHICS REFERENCE NO: N09/10/270

RE : APPROVED

At a meeting of the Health Research Ethics Committee that was held on 11 November 2009, the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 15 March 2010 for a period of one year from this date. This project is therefore now registered and you can proceed with the work.

Please quote the above-mentioned project number in ALL future correspondence.

Please note that a progress report (obtainable on the website of our Division: www.sun.ac.za/rds should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.
Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239
The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Approval Date:15 March 2010

Expiry Date: 15 March 2011

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Yours faithfully

MRS MERTRUDE DAVIDS
RESEARCH DEVELOPMENT AND SUPPORT
Tel: 021 938 9207 / E-mail: mertrude@sun.ac.za
Fax: 021 931 3352

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Appendix B

Ethical approval for project studying access to health services for people with disabilities in South Africa

3 October 2008

Prof L Swartz
Dept of Psychology

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Dear Prof Swartz

RESEARCH PROJECT: "ACCESSIBILITY TO HEALTH SERVICES AMONG PEOPLE WITH DISABILITIES IN SOUTH AFRICA"
PROJECT NUMBER : N08/07/188

At a meeting that was held on 6 August 2008 the Committee for Human Research considered your application for the registration and approval of the abovementioned project. The Committee referred the project back to you awaiting further information that was required.

This information was supplied and the project was provisionally approved on 3 October 2008 **for a period of one year from this date**. You may start with the project, but this approval will however be submitted at the next meeting of the Committee for Human Research for ratification, after which we will contact you again.

Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary to make their final decision.
Please quote the above-mentioned project number in ALL future correspondence.

Please note that a progress report (obtainable on the website of our Division) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.
Translations of the consent document in the languages applicable to the study participants, should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239
The Committee for Human Research complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Kind regards

pp
Prof PJT de Villiers
Chairperson: Committee for Human Research
RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG)
Tel: +27 21 938 9207 / E-mail: mertrude@sun.ac.za
Approval Date: 3 October 2008 **Expiry Date: 3 October 2009**

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Appendix C

Eastern Cape Department of Health approval

Eastern Cape Department of Health

Enquiries:	Zonwabele Merile	Tel No:	040 608 0830
Date:	10th May 2010	Fax No:	043 642 1409
e-mail address:	zonwabele.merile@impilo.ecprov.gov.za		

Dear Prof Leslie Swartz

Re: Enabling universal and equitable access to health care for vulnerable people in resource poor setting in South Africa

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT

PGDP EASTERN CAPE 2004 - 2014

Ikamva eliqaqambileyo!

Appendix D

Interview Guide

Interview Guide – Mental Health Madwaleni

- Tell me about your experience with your mental illness – I want to hear the story in your own words. I may have additional questions further along, but for now, just speak freely.
- From the perspective of users and non-users of primary health care:
  - What is happening when they are using the health care services (users)?
  - Why are certain people not using the health care services (non-users)?
  - What are their understandings of important factors that determine access to health care?
  - What are their understandings of health, mental illness and health related issues including profile of health needs?
  - What is their knowledge of possible and potential help?
  - What is the use and perception of services from the professional sector and the folk sector?
  - What kinds of obstacles do people face when addressing health problems, including seeking health care and accessing health services, and how do they conceptualize these obstacles?
  - What kind of coping strategies are used by the disabled person and family to cope with health related difficulties as a result of poverty?

- From the perspective of health care providers from both the professional sector (biomedicine) and the folk sector (healers and indigenous practices of various kinds):
  - How do *health care providers* understand the health care needs and usage of Xhosa-speaking users with psychiatric disabilities in Madwaleni, and how do they understand the health system's role in providing equitable and universally accessible health care?
  - How do health care providers cope with the health related difficulties of patients with psychiatric disabilities?
  - How are relevant health policies implemented in Madwaleni (in theory and in practice)?